Autistic people's perception of and functioning in space: what makes this problematic?

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I always thought about opening a restaraunt or store where the lights are dimmer, theirs only soothing noises in the backround, nice and open, every corner you turn, theres a room where you can go collect yourself... Or a restaraunt were it has a part of it secluded for people who are mentally disabled, where everything accomondates their needs, and so you can be yourself, and not have to worry about the stares or the people talking about you behind your back. I would do anything for all of that! [I have retained the author's spelling] (Age1600, 2007)

Abstract

In this study, I take autism related research beyond the laboratory, to understand how autistic people's spatial perception and functioning affects their daily lives. Many autistic writers discuss difficulty in processing sensory and social stimuli from the physical and social environment. These difficulties sometimes lead to physical collapse or an emotional outburst, resulting in physical pain or conflict with those around them. To examine this, the analytical framework of this thesis takes a broader perspective of space beyond its visible attributes and sensory effects and views autism as difference rather than disability. To do this I apply Ben Shalom's typology and her integratory theory of autism, which suggests 'impaired' preconscious processing in the domains of motor, emotion, memory, and sensation/perception. From this, I conclude that differences in preconscious processing make it difficult for autistic people to read spatial and social cues and adjust to them fast enough. This is complicated by autism often being an invisible disability. This makes it difficult for those encountering autistic people to understand that differences in demeanour are often due to orientation rather an intentional wish to cause spatial disharmony.

This study employed a case study research frame, informed by critical, feminist and disability research, employing 'go-along' interviews, an unstructured, and user-led, interpretative, ethnographic method. This involved accompanying autistic people during their daily activities, followed in most cases by intense discussion of the issues raised. Analysis took the form of on-going dialogue with the participants that was then triangulated with autistic authored and academic accounts.

Dedication

To those who are told their lives are not worth living, who do not expect to find a toilet they can use, who have to hide their difference for fear of losing their jobs or their children, who have emotional and other aspects of their lives belittled, are ignored, patted on the head, talked about as if they weren't there, stared at, manhandled, provoked, chased or otherwise abused because of their perceived difference from those who distinguish themselves as able-bodied and/or neurotypical.

Also in memory of those who influenced this work, but who died before its completion

Colin Wilfred SSF, brother of the Society of
St Francis who by his example taught me
how to treat others with respect and dignity.

David Morris artist, filmmaker, disability activist, advisor to the Mayor of London, who believed in me and respected me for who I am.

Mary Colley founder of DANDA who had a no-nonsense respect for my work.

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Chapter 1: Introduction

The objective of this study is to understand through autistics'[1] eyes, what makes their daily perception of and functioning in space so problematic that many have difficulty in accessing employment, leisure and other social activities that the typically developing population take for granted. In autistic authored writing, the most commonly discussed spatial issues concern sensory aspects, due to differences in sensory processing and integration of information from the environment. This can affect all five senses, plus those of proxemics and proprioception[2]. This often has a knock-on effect on autistics' ability to read the social cues of space. Others whose primary issues concern social functioning, report issues in reading spatial and social cues. As we will see this affects the spatial comfort of those sharing space with autistics often limiting their social participation due to misunderstandings and assumptions regarding their social competence. These concerns are explored through the creation of mutual, working relationships with autistics as I join their daily lives as participant observer.

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[1] Note: I use 'autistic's the majority of the time as it is widely used by user-led organisations of autistics, individual blogs and websites and is intended to be in line with the American Psychological Association, who argue for the use of the preferred term of the community (APA 2001:72), (Brown 2011), (Sinclair 1999).

[2] Proprioception is the term for conscious and unconscious processing which tells the body where it is in space. Conscious proprioception facilitates complex motor activity, while unconscious proprioception coordinates basic posturing during sitting, standing and movement (Johnson and Soucacos 2012).

To do this I needed to understand the values of the communities of autistics I worked with. I did this by going where autistics go, spending many hours at user-led autism conferences, social events and participating in user-led organisations of autistics. I discovered that many autistics rejected medicalised descriptions of autism and this determined my approach to the study. Many autistics argue that the focus on finding a cure for autism is an affront to their personhood; diverting money away from support services that would improve their quality of life (AFF, 2009). Autistics also argue the emotive nature of these campaigns reinforces negative stereotypes of autism, making it difficult for them to get employment and appropriate services (Burne, 2005; Solomon, 2008). Thankfully these concerns are now being debated by scientific researchers, including discussions regarding the use of participatory research methods (Pellicano et al., 2011).

Throughout this study I witnessed the autistic community pushing to be accepted on their own terms; to be seen as different rather than disabled; arguing for autism to be accepted as a culture in its own right, through organisations such as the London Autistic Rights Movement (LARM), Autscape and DANDA in the UK and Autreat in the USA (ANI, 2011; DANDA, 2011; Davidson, 2008:792f; LARM, 2011; Robertson, 2007; Solomon, 2008). This does not mean that the autistics I met are against therapeutic intervention, or deny the negative aspects of autism. Their argument is that people should listen to their point of view and respect their differences (Hurlbutt and Chalmers, 2002). However, whilst my views align with theirs, emotionally and intellectually, their argument could be seen as illogical, arguing simultaneously for support services and that they are different rather than disabled. Nevertheless, many other nondisabled cultural groups also argue for specific services. Baron Cohen suggests the legal system may need to be revised to allow statutory service

provision of services to include those who define themselves as different rather than disabled (Baron Cohen, 2000:498).

Following the community's argument that autism is difference rather than disability, most of those I met objected to being referred to as 'people with autism' saying it makes autism sound negative (Sinclair, 1999:311). Therefore after much thought concerning whether to use autistic people or autistics, I predominantly use 'autistics'. This is the term used by most of the people I meet through user-led organisations such as Autscape, Autreat, LondonARM and DANDA and is in line with American Psychological Association guidelines (APA, 2001:72:72). Similarly, there are other problematic questions regarding the use of language. Do I use difference, or impairment, needs or requirements[3], typically developing and so on. I am keen not to distract from the central imperative of this research – understanding autistic spatial experience by engaging in semantic and political debates regarding language. I prefer to use, difference, requirements, support or assistance and demeanour where this would not confuse the reader. In UK disability movements, they are perceived as more neutral than 'behaviour'[4] or 'help' for instance, which have pejorative

[3] 'Requirements' is preferred by many English disabled people. They do not like the needy connotation of 'need'. Similarly, they have reclaimed 'disabled people' rather than people first language as reflecting the reality of their marginalised status (DPI 2010).

[4] 'Behaviour' is often used pejoratively in relation to those with social disabilities including autism. For instance 'challenging behaviour', which Clements suggests should be reframed as 'behaviours that challenge us' (Clements 2009); i.e. the majority population, indicating the imbalance of power, between those who define behaviour as challenging and those who are perceived to exhibit it, as we will see in the case studies in Chapters 4 and 5.

connotations in relation to autism. Others may differ, and despite the aim of this study being to understand autistics' experience of space, it cannot separate itself entirely from discrimination faced by autistics. Therefore, I am keen for the reader to know I consider language crucial in challenging discrimination.

I also wanted to refer to the participants as co-researchers, several participants fitting this description. However, as a doctoral study, it is meant to have one researcher and despite describing its participatory nature, the use of co-researchers rather than participants may cause confusion. Therefore, after discussion we decided to mention the dilemma as I am doing now, and then to use participants instead of co-researchers throughout to avoid confusion. Autistics' pursuit of self-determination largely fits with my philosophies regarding human agency and self-actualisation.

These determine the research philosophies informing this study, those of disability and feminist research, underpinned by ethnographic and critical methodologies.

Having introduced my research area I will now provide my justification for carrying out this study, my motivation, research philosophy, a statement of the problem and its context, its purpose and objectives, followed by my research question.

Justification for carrying out this research

The associated costs of supporting autistics in the UK is estimated to be £28 billion and 36% of this is due to unemployment (Knapp et al., 2009:333). Exclusion from employment, involves other costs apart from benefit and support costs. These include loss or underutilisation of the purchasing power of autistics, the loss of their skills and profit generated from their labour (Department of Health, 2010).

Unemployment is linked to other costs such as expenditure on poverty related ill health and social exclusion (Department of Health, 2010).

My motivation for carrying out this research

The idea for researching this topic emerged when I was sitting in a residential home for young people with learning difficulties. I was sitting in an armchair, the autistic young person I was supporting had, without malice thrown himself on me for the third time, followed by smiling close to my face, and we were both bored. I was trying to contain him, as we shared the room another autistic person who was hypersensitive, perceived by staff as difficult to manage, creating a tense atmosphere that could have resulted in a violent incident. We were in a well-appointed living room, if you like pine furniture, yellow and blue flowered wallpaper and dado rails. There was a huge flat screen television, blaring out a soap opera and a box of toys suitable for a toddler, not adolescents. As a new worker, I had accompanied him that morning on a walk with his link worker, who held his hand tight and marched him through a wood and a park, preventing him from running around or playing on the equipment. The worker was afraid he would sit down and refuse to go home: however, when we returned we had nothing to do, frustrated, my mind wondered at the futility and unfairness of the situation. I thought there has to be something better than this. I was taken back to a holiday where I had supported a group of young people with learning difficulties and almost no speech. They lived in a residential unit, in the grounds of a large country house. Their lives consisted of living in the unit and going a few hundred yards each weekday to an activity centre in the grounds. A decision was made they should have a holiday and all of a sudden they were uprooted to unfamiliar surroundings and expected to enjoy the experience. We were all miserable and the young people could not tell us why. Therefore, we were reduced to 'crowd control' - keeping them safe

and containing their behaviour. When I returned from my thoughts I decided to find out why the young people had been so distressed, and what I as a landscape architect, care worker and one-time professional social worker, could do about it.

The questions that came to mind were:

- What was it about the environment that was so distressing
- What might the people I was working with have said if they were verbal
- What can I do as a designer to create places where autistics can have a good time

I was also reminded of a visit to a large psychiatric hospital in the seventies where we were shown a room with huge glass windows on all four sides, on top of metre high walls. Five women dressed in mismatched clothing, sat scattered around the room on wooden chairs, which stood on vinyl flooring. One woman had with her head in her hands; we were told this was the sum of their existence. They did not speak or engage in any activity, just shuffled, accompanied by staff from the room, to bathroom, to dormitory and back again. When we were shown the dormitories, there were only beds and lockers, with no evidence of any personal possessions. Their clothing was one of about four styles available to the women in the entire thousand-bed hospital. The dresses had a slit down the back, presumably meant to make going to the toilet easier. Their clothing was shared. The space they inhabited personified the phrase ‘warehousing’ and is very similar to Alison Lapper's experience of being brought up in a similar institution for disabled children (Lapper and Feldman, 2006). This space and the ideology that created it objectified its residents, the extent to which is evidenced by a study carried out in 1980 that was about the time I visited this hospital. The study found introducing toys into the day

room of five profoundly 'retarded' girls reduced self-stimulation and self-injury, surprise surprise (Horner 1980 quoted in Nordquist et al., 1991:135). I later spent a summer working in a home for children with learning difficulties. The space was full of noise. They also had very little speech, were constantly shouted at and sometimes manhandled, despite it being apparent that they often did not understand what was being said (Williams, 1992:196).

Research Philosophy

I will now describe how these incidents inform my approach to this study. When I considered why the incidents had such an impact that I would spend four years studying space and autism, I was taken back to my school days, where I felt my ability was either ignored or undermined. This was due to the arbitrariness of the school's need for conformity manifested in a culture of blame. This had nothing to do with learning, respecting me as a person, or finding out what I needed to learn. The school environment, although not as harsh as the hospital, came from a similar mindset that did not consider the self-defeating, dehumanising, nature of control, at the expense of maximising the potential of its pupils. The one constructive aspect of school was that it paradoxically imprinted the Christian humanitarianism of the headmaster in me the through his constant retelling of Christian gospels. A major theme was the imperative to create a fairer world which has stayed with me, given momentum through my contact with the Society of St Francis, an Anglican religious community that emerged from the Anglo-Catholicism of the Oxford Movement in the 1830s (Pusey House, 2009; Society of St Francis, n.d.). Franciscan spirituality is rooted in value of all things, people, art, animals, and endeavour. This means it is inherently political, particularly as presented by Kenneth Leech and Archbishop Desmond Tutu (Leech, 2006; Society of St Francis, n.d.; Tutu, 1999). Later events

such as visiting South African Townships as the apartheid regime came under increasing pressure, exposed me to the philosophies of radical educationalist, Paulo Freire and Carl Rogers, the founder of person-centred psychology both believe in human agency and self-determination (Freire, 2008; Rogers, 2004). In recent years, I discovered Ubuntu, an African consensual, social and communal philosophy which also emphasises non-hierarchical relationships and respect for the individual on the basis that we are all part of one another and therefore equal; if one person *'…is diminished then others are humiliated or diminished…'* (Tutu, 1999:35).

These philosophies instilled respect for the uniqueness of every individual and their right to self-determination, providing it does not impinge upon the rights of others. Having significant involvement with the Franciscans led to contact with homeless people, the gay rights movement, and the beginnings of the impact of HIV and AIDS and the anti-apartheid movement (Br Samuel SSF). It created in me the desire to understand social issues by direct involvement. These experiences shifted me from being a 'helper' who saw people as victims to viewing people as agents with strengths and skills to address their own issues (Rogers, 2004:351).

At this time, I was also providing supportive lodgings for people returning to the community after living in a psychiatric hospital. They did not seem particularly ‘mad’, leading me to question what madness was and why they had so little power, in one case having been in hospital for 40 years. I became aware that some people are treated differently due to socially created and perpetuated historic assumptions concerning what is normal or acceptable, particularly in relation to spatial demeanour. This made the arguments of Foucault and Laing compelling, especially their assertion that difference is socially constructed, depending on who controls the

discourse. Foucault's observation that only those with certain qualifications and worldviews are allowed entry into the professions showed me how divisions are perpetuated, enforcing stereotypes and social control of those who appear different (Foucault, 1995; Foucault and Faubion, 2002:120). To illustrate the arbitrariness of these divisions, Laing argues socially acceptable demeanour involves behaviours such as rejection, denial, splitting, and projection, perceived as deviant in those diagnosed with psychiatric illness. Therefore he suggests society rather than the individual is mad (Laing, 1990:23-25). Whilst informing my research 'positionality' and research design, these arguments influence my perspective as a landscape architect and social worker. My first tenet is that people know what they want. Therefore my first task as a designer is to consult the users of the space, rather than as often happens, think of a design concept (Poole, 1994). This leads me to conclude that successful design should be a consensual, collaborative process based on mutual respect (Day, 2003:viiii). In this vein I agree with Seamon who argues space must be designed from the inside out by the people who use it, designers and policymakers acting as 'environmental midwives' who use their experience to resolve design issues faced by clients (Seamon, 1993: no page numbers).

This led to an interest in design related research which argues that certain groups – such as the young (Woolley and Johns, 2001), disabled people[5] (Kitchin, 1998) and homeless people (Snow and Mulcahy, 2001) are designed out of space, especially public space (Atkinson, 2003). The combination of these experiences and ideas

[5] Many disabled people in the UK, prefer this term rather than people with disabilities, to indicate the barriers they face.

inform the critical lens through which this study is undertaken, based on the assumption that we are all equal, know what is good for us and can self-actualise. The prerequisite is that I need to constantly challenge inherited social values that shape my social behaviour, manners, customs, and conventions regarding autistics, taking nothing for granted.

Statement of the problem

Context - Autism

Sensory processing and integration issues affect many autistics' ability to function in indoor and outdoor environments (Gerland, 1997; Grandin and Scariano, 2005; Williams, 1998:20). This causes varying degrees of distortion of the senses of hearing, smell, sight, taste, touch, plus motor planning and proxemics, (Bogdashina, 2003: chap 3). This is further complicated for some by issues with the integration of memory and emotion (Ben Shalom, 2009:589; Kern et al., 2006:480; Spencer et al., 2000:2765). Effects can range from uncomfortable to acutely painful, making many environments intolerable (Caldwell, 2005:42). Caldwell argues the 'world is a swirling kaleidoscope' never settling for many. Sinclair describes difficulty with monitoring and processing, changing sensory inputs fast enough to produce the required outputs (Caldwell, 2005:42; Sinclair, 1992:4). Not all autistics are affected; the senses involved and degree vary within the individual and across the spectrum. Sometimes from day to day and for those severely affected from moment to moment. This heterogeneity of experience confounds existing scientific approaches due to the inability to identify a control group resulting in little research in this area (Grandin quoted in Beil and Peske, 2005:xi).

Sensory issues are not just limited to the five senses. Motor planning issues make many activities that are automatic for typically developing people, conscious ones for autistics. Sinclair describes plugging in his eyes in order to make sense of what he is seeing and Williams says rooms are a vague blur until someone points out the audience (Sinclair, 1992:4; Williams, 2009). Sinclair states he has to find his legs before he can walk; Gerland describes not knowing where her body is in space (Gerland, 1997:130; Sinclair, 1992:4). Ben Shalom illustrates in her paper how autistics with visual processing issues see the detail before the whole. For instance, seeing something white, round and one circle within another, before seeing it as a plate (Ben Shalom, 2005:643).

Under or overstimulation, whether sensory or social, can result in melt or shutdowns, due to many autistics' inability to adjust quickly enough the demands of space. Complete physical collapse or shutdown, can occur resulting in the person's body literally shutting down, they may appear to have fainted, and not be able to speak or move. Others may have meltdowns, often associated with not being able to process the cultural and social demands of space. The results of this varies, appearing drowsy, bursting into tears, panicking, running away, screaming, appearing aggressive, becoming immersed in pattern or an object in the environment, spinning objects or the body, hand flapping and so on (Murray quoted in Burne, 2005). The latter are compensatory strategies, still often not fully understood even by those working closely with autistics. Another issue is autistics often do not appear disabled and/or have fluctuating abilities. These depend on their physiological and psychological state as they respond to the social, sensory, and physical demands of the space.

Uncertainty regarding social interaction is another major issue for some, exacerbated by sensory issues. Many autistics describe themselves as being on the wrong planet, which is also the title of a major internet discussion group (Miller, 2003; WrongPlanet.net, 2004-11). For those affected, differences in understanding the social and cultural norms of the majority population may have a detrimental effect on their social and spatial inclusion. Accounts of this were crucial to my developing an understanding of space beyond its physical and sensory properties, to incorporate the social as an essential component of space.

Context - Policy and legislation for environmental design

When I began my research, despite the Disability Discrimination Act, 1995, replaced by the Equality Act 2010, policy and legislation rarely mentioned sensory or social requirements apart from those of deaf or blind and visually impaired people (CABE, 2006; 2008; Great Britain, 2010). Recently, *BUILDING BULLETIN 102: Designing for disabled children and children with special educational needs*, discusses acoustic and spatial layout requirements of autistic children. Glasgow City Council have also published *A Practical Guide for Registered Social Landlords* (DCSF, 2008; Glasgow City Council, 2011:15,25,32,65,149,150). This has brief a chapter on the spatial requirements of autistics, addressing some of the issues raised in this thesis, such as noise, homelessness and harassment (Glasgow City Council, 2011). Apart from this any mention of the spatial requirements of autistics appears to be absent from statutory policies governing built and outdoor environments in the UK (ODPM, 2004:43,70). *British standard, BS8300*, provides limited guidance that would improve accessibility for those with sensory issues, for instance avoiding stripped patterns for floor and wall coverings, avoiding glare, use of visual cues, and attention to acoustics. However, this is in the context of visual and hearing impairments, with

only one mention of learning difficulty (BSI, 2009:37,44,47,49,75,123). I am a member of the British Standards Neuro-diversity working group, whose aim is to formulate spatial design guidelines for neurodiverse people including those with autism. I hope these will be incorporated into other accessibility guidance.

Context - space

From the above discussion it can be seen that the accessibility requirements of autistics are absent from most legislation and policy concerning the built environment. Part of the reason for this is the focus on the requirements of wheelchair users and those with hearing or visual impairments. Additionally most design of the built and natural environment[6] focuses on its visual properties, neglecting its sensory impact and considerations of comfort and sociability. I suggest the reason for this is lack of consultation with prospective users when designing buildings. Franck and Lepori argue that consultation and a re- evaluation of the role of the senses in architecture would create an opportunity for sociocultural as well as personal transformation to create 'community conscious design' (Franck and Lepori, 2007:6).

Space, design and disability

The social model of disability underpins UK policy and legislation regarding disabled people's rights, for instance, The Disability and Human Rights Commission guidance on the Equality Act 2010, and the National Audit Commission's guidance Supporting People with Autism Throughout Adulthood (DRC, 2005; National Audit Office, 2009b:4,11). The social model argues poverty, disadvantage and social exclusion is

[6] In the context of the UK there are almost no environments that have not been modified by humans

not the result of disability, but due to attitudinal and environmental barriers (DRC, 2005:2,172). The opposite argument is that of the medical model, which argues 'overcoming' disability is the responsibility of the individual (Barnes and Mercer, 1997). From the overview of policy above, it is apparent that society disables people through spatial design, paying limited attention to, or neglecting the accessibility requirements of certain groups, including autistics who experience social and sensory impairments, rather than disabilities that require the use of a wheelchair. However, I suggest the social model's focus away from 'impairments' obscures the complexity of individual experience, especially of autistic and other people's social 'impairments' or differences (Gilbert, 2004:300; Humphrey, 2000:67; Pinder, 1997:302). However, during the study I met many autistics who argue they are different not impaired.

When discussing disabled people's experience it is easy to talk at length about discrimination and the discomfort many typically developing people feel in the presence of disabled people. However, many participants in this study did not talk in terms of overt discrimination, such as illustrated by ABC News, who used actors to play a family with an autistic child and a customer complaining about his behaviour . However, the discrimination the majority of participants experienced during the go-alongs was subtle and elusive but despite this had a powerful exclusionary impact. The participants discussed their experiences on a more personal level in terms of the subtleties of not having their spatial experience and/or social demeanour understood in most cases, rather than intentional discrimination. This is not to say that I did not witness overt discrimination of autistics when I attended meetings on behalf of the London Autistic Rights Movement. The most common being attempts to silence autistic colleagues or using the ruse that the person will speak to the autistic person

later, rather than include them in on-going discussions (National Audit Office, 2009a).

The effect of the medical model

What I feel is more relevant in relation to the study is the effect of the medical model on design. The medical model places responsibility on the individual to overcome their disability until a cure is found. This has meant that designers have viewed disability as a temporary state, not worthy of detailed consideration and therefore have not considered the removal of disabling barriers as a moral and social imperative (Campbell, 2010:79; Kumari Campbell, 2008:157). Another reason for the neglect of accessible design has been the historic influence of designers such as Le Corbusier. His architectural proportions were based on 'modular man', and the ‘normal’ body rather than the diverse requirements of disabled people, older people, people with temporary disabilities, and those with pushchairs, wheeled suitcases and briefcases (Imrie, 2003).

Another neglected element that affects autistics, mentioned above is the negative impact of designers’ focus on the visual impact of buildings, instead of spatial comfort and sociability (Pallasmaa, 2005:10). The focus on the visual also being at the expense of designers fully understanding users' experience and use of environments (Rapoport, 1994:72). Moving the focus from visual to sensory comfort and sociability is a crucial accessibility requirement for autistics, their physiological, psychological, and physical well-being being inseparably tied to their effective functioning in space and therefore their acceptance (Harries quoted in Paterson, 2011:271; Stokols and Clitheroe, 2010:97).

Existing spatial design for autistics

The following discussion will show that almost all design for autistics is carried out without consulting them. Most existing spatial design for autistics is being carried out on a design by design basis, with very few practices specialising in design for autism. Most architects focus on physical and sensory aspects, using finishes and layouts to create calm environments. However, Beaver briefly mentions substituting corridors with circulation spaces, to encourage sociability and spaces where the children can determine the activity (Beaver, 2006; Beaver, 2010; Humphries, 2008). Most of this discussion centres on educational settings for autistic children, consultation including carers, autism professionals and architects with little to no input from autistic children or adults (Beaver, 2006; n.d.; Brooks, 2010; Hebert, 2003; Humphreys, 2005; Humphries, 2008; Janzen et al., 2006; Khare and Mullick, 2009; Plimley, 2004; 2006; Plimley and Bowen, 2006; Shabha, 2006; Vogel, 2008; Whitehurst, 2006a; b).

Brooks, a doctoral researcher investigated classroom design for autistic children. Her data was obtained by observation, questionnaires, staff and parent reports, mostly relating to the physical and sensory environment (Brooks, 2010:135). However, it includes important practical considerations such as the provision of accessible toilets with showers in the immediate vicinity of classrooms (Brooks, 2010:250). The children were only included in discussions about their new classrooms, after they had been reconfigured, photographing their favourite parts with their support workers, not the researcher (Brooks, 2010:245).

Mostafa, similarly used questionnaires to consult with parents and teachers to modify the acoustics and spatial sequencing of a school classroom to improve sensory comfort (Mostafa, 2008:192f). This included creating 'escape spaces' and partitioned

study areas, to deal with sensory overload and visual distractions (Mostafa, 2008:193). Mostafa did not consult directly with the children (aged 6-10 years) or refer to first-hand accounts of autistics' sensory experiences. Khare and Mullick identified spatial design parameters from a review of autism related educational literature and measured them against different school environments (Khare and Mullick, 2009:48). They conclude there is a strong correlation between design and performance in school environments, arguing that addressing autistic students' spatial requirements improves the school environment for everyone (Khare and Mullick, 2009:54). Khare and Mullick argue that the benefits of an inclusive school ripple out through its students to create a more inclusive society (Khare and Mullick, 2009:45). A similar argument is made by Woodcock et al, who argue their findings reveal a range of issues that should be considered in the design of all learning environments so all children can reach their full potential (Woodcock et al., 2009:254). Ponte observed the effect of the school environment on three autistic students' ability to keep on task, socialise, and also assessed the presence of stimulatory behaviours (Pont, 2008). For her study, Pont surprisingly gained the consent of the parents rather than that of the students, suggesting that if the students knew they were being observed this would affect their behaviour (Pont, 2008:10). She did not discuss the ethics of doing this, illustrating the ease with which autistic consent can be bypassed.

The above studies and most existing design shows a focus on controlling and modifying behaviour and creating calm environments; I do not denigrate this; all children should have the opportunity to become whoever they can be. However, Woodcock et al's research went beyond the educational considerations above, creating pleasurable, low arousal environments. These allowed the children to 'tailor'

their environment using interactive video, manipulating patterns on huge screen, using their body movements (Woodcock et al.:6; Woodcock et al., 2009:252). However, Woodcock et al said they could not get most of the children's views of the activity as they were young and had difficulties with communication (Woodcock et al.:2).

Current research with autistic children

Krawczyk's on-going research explores the role different environments have in the lives of autistic children. She uses open ended, go-along interviews so that they can show and/or tell her about the places and why they enjoy them. She also asks them why they like certain places, the types of activities that take place there, the amount of time they spend in these places, and who they play with there. Her findings highlight how children's sensory issues in certain environments create barriers while other places provide affordances for sensory needs. The significance of special interests in determining environmental preference, use and helping to create bridges for social connections; and the importance of natural settings, virtual environments and technology (Krawczyk, 2011).

Scott also used participatory research with autistic students aged 13 to 15 years; pairing them with architectural students for a week. They explored their perception of place through classroom activities, visits to art galleries, and visual media (Scott, 2009:16). Krawczyk and Scott's research goes further than the research discussed above in working alongside autistic children. Scott's importantly, looking at how autistics can be involved in design processes which the other studies do not. However, I suggest Scott's study would have benefited from involving autistic adults who could have supported both sets of students to develop a closer interaction. This

could have led to a deeper understanding of the autistic children's experience of and perception of place.

Research using autistic authored autobiographies

Moving on to autistic adults, Davidson carried out a literature review of forty-five autistic authored autobiographies, attempting to formulate recommendations to challenge barriers to their socio-spatial inclusion (Davidson, 2010:305). Her findings again focus on sensory issues with little explicit discussion of social issues. Davidson's conclusion advocates mutual understanding between autistic and typically developing people to create real inclusion (Davidson, 2010:306). She like Khare and Mullick argues that inclusion is two-way, benefiting both autistics and society.

Research with autistic adults

A study by Baumers and Heylighen also reviewed autistic authored autobiographies, including a day's observation in a residential unit and the appraisal of a university building with an autistic student (Baumers and Heylighen, 2010a: para 12). From the day's observation, they were only able to conclude that the activities were complex, probably because such a short visit meant they could only observe, rather than fully engage with the residents (Baumers and Heylighen, 2010a). More recently they investigated the design decisions made by an autistic individual in the planning of their home (Baumers and Heylighen, 2011).

Bontempo also worked with autistic adults, examining their sensory processing patterns in the workplace; using telephone interviews, finding that being able to control, predict and have flexibility in the work environment was very important to them. Some of her participants also used compensatory strategies to manage the

sensory environment, saying their sensory difference contributed to their superior technical skills (Bontempo, 2009:52).

Another study, by Brand involved four autistic adults and 12 autism/spatial advisers to create design guidelines for group homes in the UK. The main issue with this study is that three of the autistic adults consulted lived in their own homes, only one sharing an apartment, so they may not been aware of the many socio/spatial issues in shared accommodation (Brand, 2010:12,13). Additionally they were outnumbered three to one by professionals in the consultation process (Brand, 2010:3).

However, other research is more participatory, that by Ahrentzen et al contains the broadest consideration of autistics' spatial requirements I have found to date. This is despite having a section entitled resident base design goals, without appearing to have directly consulted with autistics or autistic led organisations (Ahrentzen et al., 2009:21). Sensory issues, safety, and security are still main issues. However, Ahrentzen et al include aims such as maximising familiarity with the environment; the provision of opportunities for autistic residents to control social interaction; to foster choice; independence; health and wellness; enhance dignity; affordability and accessibility, and support in the surrounding neighbourhood (Ahrentzen et al., 2009:22ff). Unlike many of the studies and discussions I referred to above, the aims of their study recognise the personhood of adult autistics, supporting their social inclusion.

As we have seen so far, spatial research does not include the views of adult autistics and lacks detail. Most autism related research and discussion focuses on what autistics do, not how and why they do it, especially in the context of daily spatial and social interaction with those sharing their lives. The one study I found, which does

this is Nordquist et al's, who observe the effect of newly reconfigured classrooms on the relationship between autistic children and staff in a state run American institution. They found staff interaction with the children through smiling and affectionate attention rose. At the same time the children's use of play materials increased and their behaviour improved (Nordquist et al., 1991:135).

One of the few people to discuss social aspects of design in any detail is Whitehurst, reviewing new student accommodation at Sunfield School, designed by Beaver. She says the new design improved interaction through the creation of earlier mentioned circulation spaces and a secure outdoor play area. However, there is still a pervasive emphasis on security and monitoring of the children (Beaver, 2006; Whitehurst, 2006b:37f).

Plimley's study with her Webautism students is the only study I discovered that discusses the spatial requirements of autistics and the social qualities needed by those supporting them in residential settings (Plimley, 2004:36). During the current study some of the 'people' aspects identified by Plimley's students became issues with some of the participants in this research. Issues such as my understanding of them, being able to prioritise what was important, weighing up 'conformity issues'; these concerned expectations and what I could tolerate. For instance, I had an innate view of how respect was shown, I discovered when it was not, this did not equate to intended disrespect. I learned to focus on what was important, sometimes staying alongside no matter what (Plimley, 2004:36).

To sum up, my review of the discussion and research in this area shows many beneficial guidelines have been developed. The work of Ahrentzen et al and recent discussion by Henry, advocating the exploration of the environmental preferences of

autistics gives hope (Henry 2011c). However, Henry's discussion, at the time of writing still focuses on sensory aspects of design, although he provides comprehensive criticism, of previously mentioned research by Mostafa, and the limitations of observational research in relation to architectural design (Henry 2011a; b; c; d; Mostafa, 2008). The focus on sensory issues could be because it is easier to articulate guidelines for sensory comfort rather than elusive aspects of sociability.

Despite discussions presented above inconsistencies still exist in spatial guidelines (Henry 2011c). For instance replacing florescent lights with recessed lighting with reflective silver casings, which are visually painful for many autistics, shown in figure 1 (Beaver, 2010; Beaver, n.d.).

Figure 1. Showing recessed lights with reflective casings in a design intended to be low arousal. The ceiling is visually complex with holes in the acoustic panelling, which some autistics may be impelled to count. Photo: Beaver 2010

Other concerns include suggestions to increase the number of exits and entrances to corridors and day rooms to make the interior more visible, so residents can choose whether they want to be there and can exit easily. The unintended consequence of this, I suggest is the creation of through spaces and visual clutter rather than relaxing,

calm spaces, that create a significant element of privacy, needed to prevent shut and meltdowns (Brand, 2010:32,40).

I suggest these contradictions do not come from the lack of will of those discussing and designing for autistics, but because, apart from Krawczyk, Baumers, Bontempo and Scott, they do not consult with autistics. Figure 2 below, shows the result, the development of designs that are in my opinion inconsistent (Henry 2011c).

Figure 2. This shows a school corridor designed to be autism friendly. Its beams cast many shadows which are difficult for autistic, other neurodiverse conditions and those with visual impairments to function (Becchio et al., 2010:10582). Photo: Iain Scott 2009. New Struan is an independent school run by the Scottish Society for Autism (SSA): Aitken Turnbull Architecture

This study suggests many issues can be dealt with through working relationships with autistics, to create a broader understanding of space as a continually changing social and physical entity. Working relationships allow real-time study of the effect of physical space and daily social and spatial interactions, including that between participant and researcher and how these affect autistic perception and functioning; something that appears not to have occurred to date (Gernsbacher, 2009:140; van

Ommeren et al., 2011:1001). A crucial aspect is the failure of typically developing people to understand the effects of autistic body language and prosody on their interaction with autistics (Kalb, 2010; Peppé et al., 2011:42). This is because the phrase ‘social and communication impairments’ does not indicate how these impairments might affect typically developing people's interaction with and reaction to autistics.

Context summary

This suggests that:

1. Current research and discussion is mostly limited to sensory issues, particularly hyperarousal, and the creation of calm, in mainly educational environments.
2. Statements such as 'social and communication impairments' do not provide sufficient detail to understand how they manifest or affect the daily lives of autistics and those sharing space with them.
3. Detailed research is required to explore wider differences in autistic functioning, for instance in memory, motor, sensation/perception and emotion.
4. There is a need to get first-hand accounts from autistics concerning their perception of and functioning in space and what makes this problematic.
5. For this, I needed to work alongside autistics, on their terms, studying their daily perceptions of and interaction with space and those they share it with.

Working with autistics as co-researchers

To begin to answer these questions, and develop my research frame and methods I looked at existing participatory research with autistics, in this context research that involved autistics as researchers, and or consulted them regarding their daily issues. This revealed a limited number of studies in the UK and the USA. These are summarised in table 1 below:

Academic Studies/ authors	**Autistic people's involvement**	**Method**
Aspects Project Beardon and Edmonds (Beardon and Edmonds, 2007)	4 out of 7 on the steering committee were on the autistic spectrum	Questionnaires completed by autistics regarding service requirements
Asperger Syndrome and Perceived Offending Conduct: a Qualitative Study. Beardon (Beardon, 2008)	Examined whether being on the autistic spectrum influenced their behaviour in the lead up to arrest and the issues resulting for the autistic person from being arrested	Interviews with autistic people
'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. Madriaga (Madriaga, 2010)	Gained insight into some of the sensory and social experiences of the participants, but did not visit any of the places with the participants	Year long, longitudinal study, using informal interviews, member checking by participants of interview transcripts

Orchestrating voices: autism, identity and the power of discourse.(Bagatell, 2007)	Nine-month study with a young autistic man to investigate his process of identity formation	participant observation and interviews including accompanying him to activities
Autism and the myth of the person alone. Biklen, Attfield, Bissonnette, Blackman, Burke, Frugone, Mukhopadhyay, Rubin (Biklen et al., 2005)	autistic people describe in detail their daily experience	Individual autistics write their own chapters in a book complied by Biklen
Autism as metaphor: narrative and counter-narrative. (Broderick and Ne'eman, 2008).	their writing challenges, dominant metaphor of autism as a disease, promoting a counter-narrative of autism as neurodiversity	collaboration between Broderick, an academic and Ne'eman, president of the Autistic Self Advocacy Network to produce an academic paper
Adults With Autism Speak Out: Perceptions of Their Life Experiences. (Hurlbutt and Chalmers, 2002)	participants are proud to be autistic and wanted to be consulted about issues affecting their lives	interviews with three 'high' functioning autistics
Memory and generativity in very high functioning autism: A firsthand account, and an interpretation. (Boucher, 2007)	examination of JS's atypical memory abilities in the context of his daily life	single case study methodology

Table 1. Studies involving autistics carried out within academia

Send in the idiots: or how we grew to understand the world.(Nazeer, 2006)	Accounts of visits to 3 former classmates and the parents of the fourth who had since died, 25 years after they had left school	Narratives of the four visits
Women from Another Planet?: Our Lives in the Universe of Autism. (Miller, 2003)	Discuss their daily lives of autistic women from their perspective	Done through collection of narratives and conversations written by autistic women

Table 2. Studies involving autistics carried out outside academia

As we can see above there is a mixed bag of methods and levels of involvement, Biklen's research is closest to the philosophical underpinnings of this study, having the ‘presumption of competence’ at its heart, corresponding with the writings of Freire, people as ‘beings who know’ and Rogers’ self-actualising tendency (Biklen et al., 2005:1; Freire, 2008:107; Rogers, 2004:351). Whilst there are also several high profile autistic researchers such as Michelle Dawson I only discovered one example of participatory research within academia of an autistic person as a co-researcher who provided and analysed the data (Dawson et al., 2007). This was in neuropsychology, using a single case study methodology to examine JS’s atypical memory abilities within the context of his daily life (Boucher, 2007).

The most detailed studies that discussed the detail of autistic people’s daily lives from their perspective were Nazeer and Kearns Miller, whose books provide far greater detail than much academic research which is often shoehorned to investigate

a particular aspect of the triad of impairments[7], rather than autistics' daily functioning (Happé et al., 2006:1219). My argument is that by having a detailed understanding of autistics' day-to-day lives, from their perspective we can gain a fuller understanding of their spatial and other requirements.

Also most of the participatory research I have read, apart from that of Hurlbert and Chalmers, the sole aim of involving autistics has been to provide insight into their lives (Hurlbutt and Chalmers, 2002:103). However, my intention is not to understand autistic daily experience but to influence legislation and policy, not only in relation to space but other aspects of autistics' lives (Mitchell, 2009; Walters and Hewitt, 2009). This corresponds with the imperative of research councils such as the Economic and Social Research Council, who provided a scholarship for this study, that research should have an academic, economic, and social impact (ESRC, 2012).

I hope the findings of this study will influence policy and design through my membership of user-led organisations of autistic and neurodiverse people and of the British Standards Committees B/559/-/5 Neurodiversity Task Group and BSI task groups – Accessibility - External Environments.

I developed the objectives of this study as follows:

- To explore autistic people's spatial experience
- To take a broad conception of space including its social, contextual and sensory aspects as well as the physical and visual

[7] That is the triad of impairments of social interaction, communication and imagination (Wing, Gould and Gillberg 2011):768f.

- To work on as equal a basis as possible with autistics, recognising the challenge of overcoming 'business as usual disablism'[8] (Kumari Campbell, 2008:152)
- To use our working relationship reflexively, through the employment of Fine's concept of the hyphen, as elaborated by Jones and Jenkins to expose our differences and how these manifest themselves in our interaction with space and each other (Fine, 1998; Jones and Jenkins, 2008)

Research question

From the objectives, I developed my central research question:

> **Autistics' perception of and functioning in space: what makes this problematic?**

And from this two sub questions:

- **How do autistics perceive and experience space?**
- **How does space, including its social aspects affect autistic functioning?**

Having set out the context, in the next chapter I present the theories of autism and space that inform the analytical framework and research design of this study. The subsequent chapters contain case studies presenting snapshots of the spatial issues encountered by the participants in this study. This takes the discussion of autistic

[8] 'Business as usual ableism' refers to assumptions made by able-bodied people that everyone functions the same way as they do, resulting in institutional disablism (Kumari Campbell 2008):151f.

spatial requirements beyond school, residential establishment walls, low arousal environments, and sensory issues to the context of autistics' home, travel, work, and leisure activities. The final chapter brings together the themes explored in the case studies.

Chapter 2: Analytical Framework

Here, I discuss the theories informing the analytical framework of this study. I begin by discussing autistic authored, autobiographical accounts of their interaction with space, before going on to looking at limitations of the medical model of autism in relation to this study. I then discuss Ben Shalom's typology and integrative theory of autism and its application to this study. Next, I discuss the theories from environmental psychology, human geography, sociology, and anthropology that broadened my conception of space to understand the functional and socio/spatial experience of autistics. Finally, I show how the resulting frameworks determine my research frame and methods.

Section 1: Autistic Autobiographies: Sensory issues

My analytical framework initially developed through reading Bogdashina's and Caldwell's books discussing autistics' sensory and perceptual experiences (Bogdashina, 2003; Caldwell, 2005). These led me to autistic authored, literary, and online accounts of autistics' experiences. I began to understand what might have been affecting the young people on the holiday I describe in the introduction. Caldwell states the sensory effects of space creates 'a swirling kaleidoscope' that never settles for many (Caldwell, 2005:42). Bogdashina and Caldwell introduced me to the sensory processing, perceptual and integration issues which affect one or more of all five senses, plus proxemics and proprioception (Bogdashina, 2003: chap 3). Autistics are usually predominantly hyper or hypo-sensitive in one or more of the senses: the effects of this can fluctuate from day-to-day in the senses affected and the degree depending on physiological state of the person (Bogdashina, 2003:53;

Clements, 2009). Such heterogeneous experiences mean research into the sensory experience of autistics has been neglected, by traditional quantitative methods; for instance randomised control trials, cannot be used due to the difficulty of identifying a control group (Grandin quoted in Beil and Peske, 2005:xi; Jarrold and Brock, 2004:82). Another consideration is that not all autistics appear to have sensory issues, hence they were not initially included in DSM-V[9] (Wing et al., 2011: 769). However, Wing et al quote Billstedt, Gillberg, and Gillberg (2007) who found that issues with sensory processing were present from early childhood, 95% still being affected at 30 years of age (Wing et al., 2011: 769). Further Billstedt et al suggest the possibility of sensory issues being used as diagnostic criteria for autism should be investigated (Billstedt et al., 2007:1108).

Sensory issues appeared to be an important determinant of many autistics' experience of space, confirmed through my reading of autistic authored autobiographies, such as those of Gerland, Williams, and Grandin (Gerland, 1997; Grandin and Scariano, 2005; Williams, 1998:20). One of the most graphic accounts of the effect of sensory overload on functioning comes from Gerland describing the sound of a moped used to torment her by the children who lived next door:

> The din made the ground under my feet disappear and I could neither see nor feel the world around me. Up and down were suddenly in the same place and I had no sense of where my feet were. So as not to fall over or explode from inside, I would grab the fence where I was standing, pressing myself

[9] DSM-5 latest edition of the Diagnostic and Statistical Manual of Mental Disorders (*DSM*-5) expected to be published in May 2013

> against it and holding on hard. I had to find something that stood still, something anchored, in a world that had suddenly become totally unpredictable. (Gerland, 1997:130)

Williams provides an example of differences in visual perception of objects experienced by many autistics through her account of receiving a doll's house for Christmas:

> I saw a big red angular object with corrugated ridges. I picked it up with the top ridge in my mouth and played the ridges as a musical instrument quite happy with my found toy…. I later moved onto the series of flattened white blocks, disassembled them from the structure and tapped at them as one does on a door before stacking them in piles according to size….I saw no doll's house. (Williams, n.d.-b)

Discussing her spatial perception, she says without her tinted glasses her bedroom, for instance, is a mass of meaningless patterns, colours and shapes (Williams, 2004:9). Similarly when she is at a speaking engagement, the audience is a vague blur until someone points it out to her (Williams, 2009).

In her writing, Grandin gives an account the compensatory strategies she uses to overcome her hypersensitivities:

> …I enjoyed twirling myself around or spinning coins or lids round and round and round. Intensely preoccupied with the movement of the spinning coins or lid, I saw nothing or heard nothing. People around me were transparent. And no sound intruded on my fixation. (Grandin and Scariano, 2005:26f).

Grandin also uses a squeeze machine, to provide pressure which lessens her anxiety and gives her a feeling of well-being (Grandin and Scariano, 2005:95f). Her account reframes repetitive behaviours from being purposeless to being essential compensatory strategies for dealing with environments that are sensory and socially hostile to autistics. It is essential to this study to understand that for many autistics, these strategies are the only way they can manage their spatial perception and functioning.

Social issues

As the study progressed, I found other accounts where sensory issues were less prominent, superseded by uncertainty regarding social interaction. Many autistics compensate by using logic to create rules for managing social interaction (Grossman et al., 2000:369). Socially many autistics argue they are on the wrong planet. This sense of alienation provides the title and theme of books such as *Women from Another Planet* (Miller, 2003)**,** *A Field Guide To Earthlings* (Ford, 2010) written by autistics, as well Sack's chapter on Temple Grandin, in his book by the same name, *An Anthropologist on Mars* (Sacks, 1995:233). Wrong planet is also the name of the worldwide, online discussion group for autistic people, which has around seventy thousand members (WrongPlanet.net, 2004-11). Discussions on WrongPlanet describe many autistics' issues in understanding the social and cultural norms of the typically developing population. These accounts were crucial in developing my understanding of space beyond its physical and sensory properties to incorporate the social as a tangible, integral space within the overall perception of space, when seen from an autistic perspective.

From the review presented in the introduction and preliminary discussions with the participants in this study, I concluded both sensory and social aspects of space are problematic for autistics. This determined the choice of disciplines used to shape the analytical framework of this study in relation to autism and space.

I will now move onto show how Ben Shalom's work frames the analytical framework for autism in this study.

Limitations of the medical model of autism

The medical model presents a restricted understanding of autistic peoples' daily lives and therefore is inadequate to inform their design requirements. The most common medicalised description of autism is of a lifelong-long neurodevelopmental condition, based on the diagnostic criteria of the triad of impairments of social interaction, communication, imagination and restricted, stereotyped, repetitive behaviour (American Psychiatric Association, 2010; Baird et al., 2006:210; Wing et al., 2002:307). Absent from this is one of the most often discussed spatial concerns of many autistics, which is difficulty with sensory processing and integration. However, as I engaged with the participants certain aspects of the triad of impairments began to resonate. These include differences in eye contact , absence of phatic conversation and body language, which I discuss further in Chapter 3, which creates 'social glue' an important aspect of sharing space with others (Lakin et al., 2003:145; Wing et al., 2011:769). However, I suggest that how the various aspects of the triad and those above manifest themselves in real time and affect the dynamics of spatial functioning is not explicitly communicated. Therefore, there is nothing tangible to inform spatial design and policies to meet autistic requirements. Making these aspects explicit and applying them is an important contribution of this study.

Impairment of social imagination also took on a new meaning once I saw its effect in the context of autistics' daily lives. When reduced to a medicalised description of 'impairment in social imagination' or 'decreased capacity to think about and predict the consequences of ones' own actions', such phrases appear pejorative. They do not show how these impairments manifest in autistics' daily lives or describe their impact on those sharing space with them (Wing et al., 2011: 769). Medicalised descriptions often blame the individual rather than accepting differences in brain functioning, for instance, that difficulty in predicting the consequences of ones' actions may be due to impaired episodic memory. Further, these descriptions rarely recognise compensatory strategies, evident in my findings, such as the use of semantic memory to support impaired episodic memory.

Limitations of current autism research

Research influenced by the medical model is generally quantitative, focusing on brain functioning, understanding the genetic basis of autism to eradicate or find a cure and developing therapies. Many autistics object to this, arguing that autism is an integral part of who they are, affronted by the suggestion that autism should be eradicated (Davidson, 2008:797). Most medical research involves testing in laboratories, where autistics are objects of research, rather than participants. Most of these studies decontextualise autistic experience, missing areas affecting their spatial functioning. Ben Shalom widened my understanding of autistics' spatial functioning beyond diagnostic criteria through her typology of autism and her integratory theory of autism. She states research has been circumscribed in the four domains of motor planning, emotion, memory, and sensation/perception (Ben Shalom, 2009; Ben Shalom and Clemerson, 2011). She argues research into motor issues has focused on imitation and learning not motor planning and execution,

which is crucial for understanding how autistics perceive and navigate space. For instance, research is often goal orientated; asking if a person can catch a ball rather than investigating their thought processes leading up to execution. Similarly, the studies focus on objects rather than daily contexts such as walking down a street, focusing on the actions of the brain rather than the body (Hamilton and Ramsey, in publication 2012). The assumption being that failing the task is because of cognitive or behavioural deficits instead of differences in motor planning (Ben Shalom and Clemerson, 2011; Vernazza-Martin et al., 2005:93).

Research into emotion also provides a limited picture, focusing on lack of understanding of the person's own and others' mental states and difficulty with reciprocity of emotion, the nuances of both being difficult to apply spatially (Gaigg and Bowler, 2007:2126). Most memory related research focuses on savantism, rather than episodic memory for instance. That is remembering past events and their associated social and spatial cues to inform in future visits (Boucher, 2007:256; Schacter et al., 2007:695f). Episodic memory also aids imagination through future thinking, such as how an apartment might look with new furniture (Wheeler et al quoted in Lind and Bowler, 2010:896). Regarding sensation and perception, the focus on weak central coherence, the tendency of autistics to focus on the detail before the whole, has left differences in sensory processing and integration unexplored (Ben Shalom and Clemerson, 2011; Happé and Frith, 2006).

As a result autistics are highly critical of medical research arguing that its findings are often imprecise and reinforce negative stereotypes preventing inclusion (Solomon, 2008). In terms of design the focus on curing autism and other disabilities takes the onus away from designers to meet autistics' and others spatial accessibility

requirements, disability being viewed as a temporary state to which no long-term design solution is required (Campbell, 2010:79).

I now move on to discuss how I applied Ben Shalom's typology and integratory theory to the analytical framework and organisation of this study, showing how it leads to a broader understanding of autistics' spatial concerns, beyond sensory issues. First, I will discuss her typology of autism, followed by her integratory theory (Ben Shalom, 2009; 2010).

Ben Shalom's typology of autism

Ben Shalom's development of her typology of autism roughly divides autistics into those with more severe sensory issues, but less severe social issues and those who have less severe sensory issues, but more severe social issues (Ben Shalom, 2010).

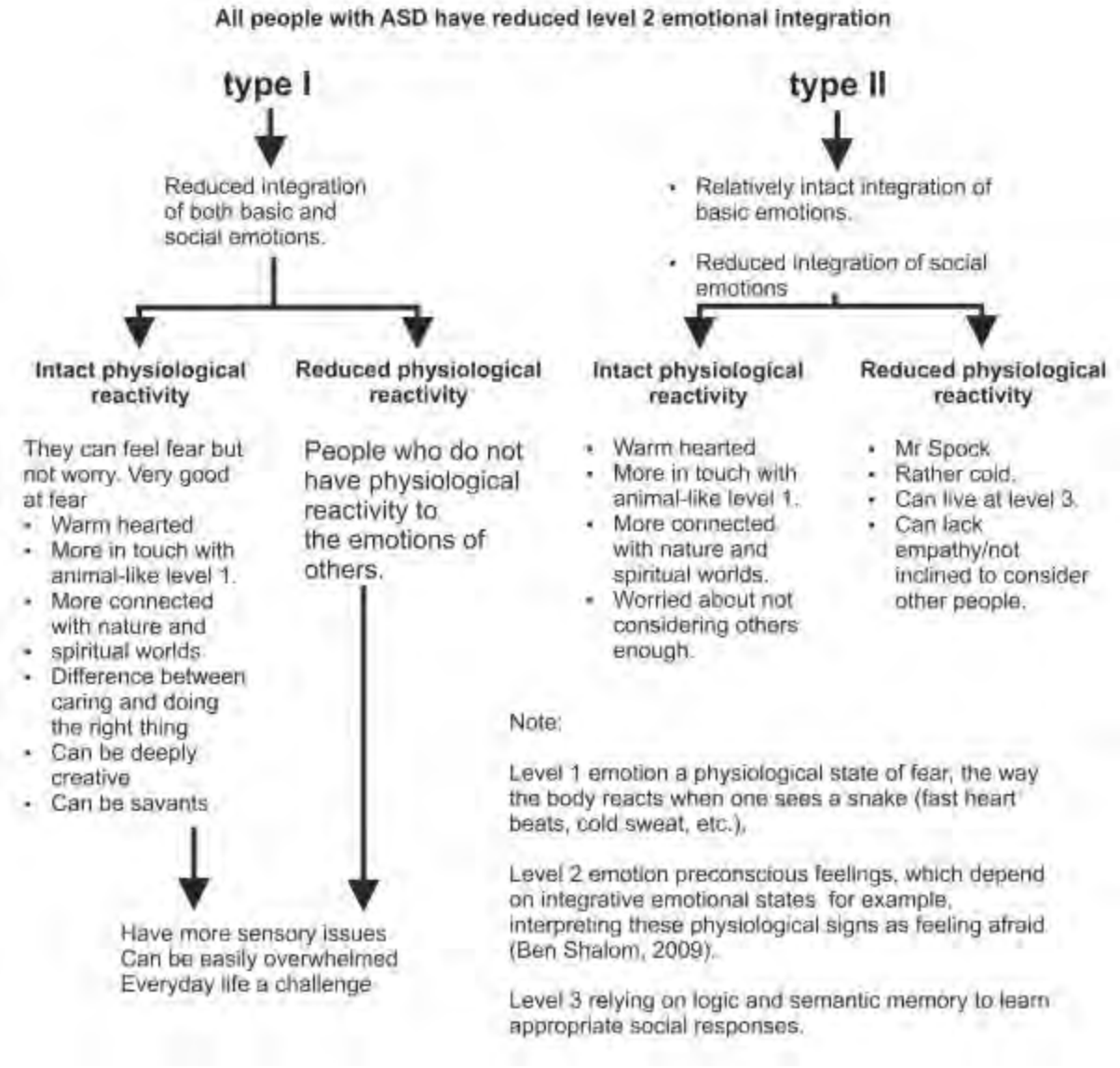

Figure 3. Ben Shalom's typology of autism (Ben Shalom, 2009; 2010).

When I reflected on the autobiographies of Williams, Grandin, Prince Hughes, and Mukhopadhyay, they all appeared to fit into Type 1. All discussed the effects of sensory issues, hyperarousal, and the use of compensatory strategies and logic to overcome impaired preconscious awareness in a wide range of areas (Grandin, 1995:26f; Mukhopadhyay, 2000:20; Prince-Hughes, 2004:25f; Williams, 1992:45). KM, who appears later, in particular appeared to fit Type I, and possibly others to some extent. The more I got to know some participants, the more areas of their

functioning appeared to fit Type 1, for instance Debra and MN who also appear later. However, I did not instigate conversations regarding diagnosis, as I felt they would be intrusive and result in leading questions instead of open-ended discussion. In addition, diagnosis would only tell me what others thought of them, rather than how they experience the world. Most of the other participants initially appeared to fit into Type II, reporting fewer sensory issues and less variation from the typically developing population in visual perception and motor planning. I found I could divide the Type II group into those who appeared to have less impaired executive functioning and those who had severely impaired functioning.

Executive function includes processes such as working memory, planning, inhibition, mental flexibility, and emotional control (Kalbfleisch and Loughan, 2011:123). Participants who appear to have less impaired executive function formed the largest group and are discussed in Chapter 3. They appear less socially active, to the extent on some occasions of appearing passive and withdrawn. This meant differences in social demeanour were less apparent, making this group less spatially threatening than those with more severe executive functioning who were more proactive and could appear overbearing. Those who appeared to have more severe executive functioning issues were more vocal, assertive and had greater physical presence. When this combined with appearing, as was case in this study to be liberal middle-class women rather than fitting any stereotype of a disabled or autistic person, this led to their presence, being perceived as unsettling or threatening even though this was not their intention. How I applied Ben Shalom's typology to the organisation of the cases in this study is illustrated in figure 4 on the next page:

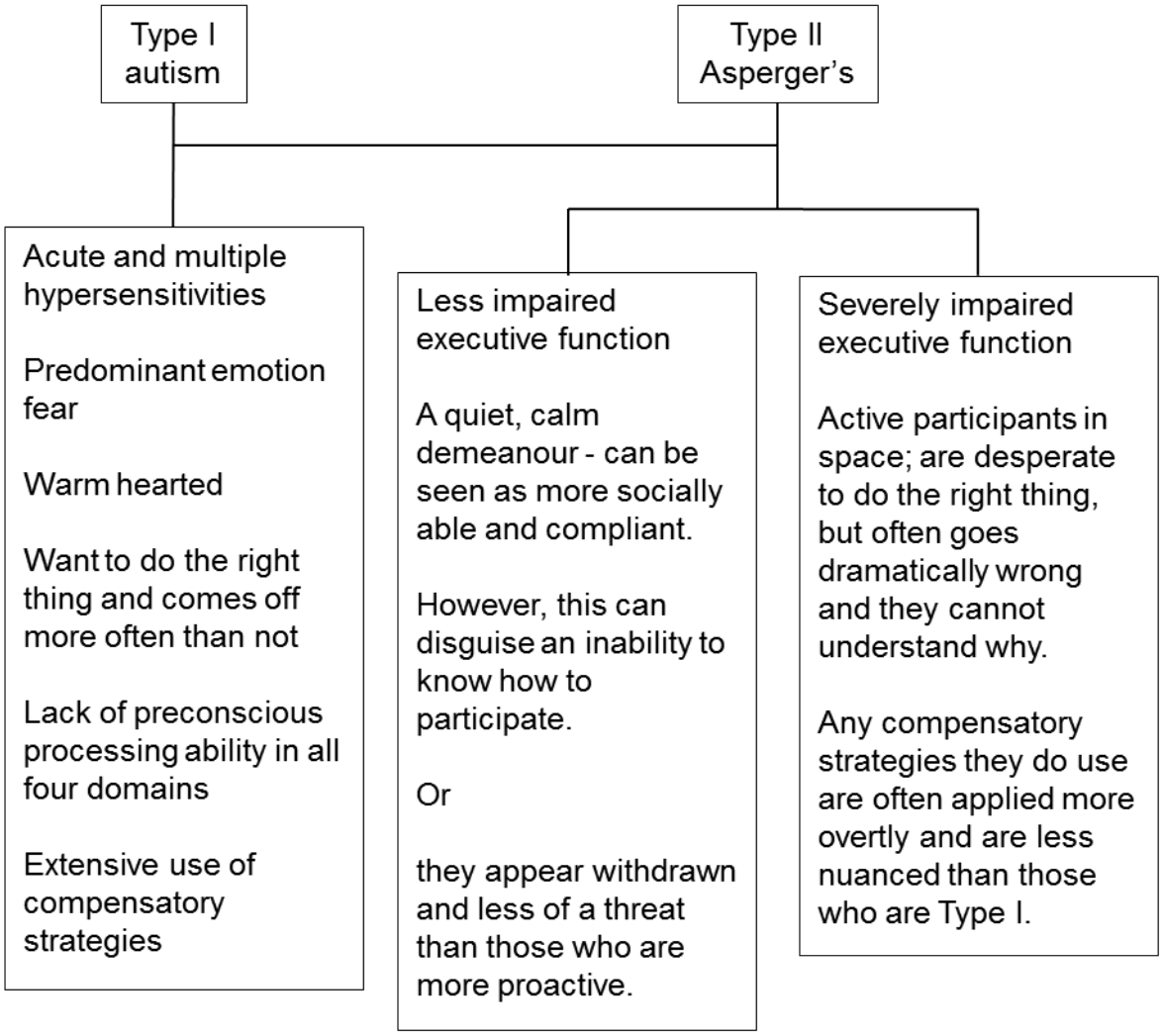

Figure 4. How I applied Ben Shalom's typology of autism to this study (Ben Shalom, 2010)

Ben Shalom's integratory theory of autism

When I began my research, I found it difficult to apply academic research to understand autistics' spatial functioning. However, once I discovered Ben Shalom's unifying theoretical interpretation of autism I gained a wider understanding of the issues. First, I discuss her three levels of consciousness, followed by discussing each of the four domains. Writing as a neuroscientist, Ben Shalom suggests there are three levels of processing internal and external information, an unconscious,

habit based level, such as that of a young baby; a preconscious integratory level and conscious logical level as illustrated in table 3 (Ben Shalom, 2009:589f). Preconscious processing is the most elusive, stimulating the brain to generate processes, but not amplifying the signal enough to reach cognitive awareness. Whereas conscious processing occurs when the stimulus exceeds the threshold for awareness (Gazzaniga et al., 2009:550f). Other neuroscientists present similar arguments to Ben Shalom, Williams et al, Marco et al, and Bertone et al, also suggesting integration of information from different domains is 'impaired' (Ben Shalom, 2009:589; Bertone et al., 2003:222; Elysa J. Marco et al., 2011; Williams et al., 2006).

Three levels of processing		
Level 3	conscious	logical
Level 2 Problematic in autism	pre-conscious	integration
Level 1	unconscious	animal like processing

Table 3. Ben Shalom's three levels of processing (Ben Shalom, 2009:589)

The three levels of processing were crucial to my understanding of autistics' spatial perception and functioning especially when analysing the data from the go-alongs and discussing them with the participants. Differences in preconscious integratory processing at level 2 were particularly relevant throughout data collection and analysis. It soon became that clear spatial activities that are instinctual for typically developing people are not for many autistics, sometimes with profound effects on

their perception and functioning. To illustrate the effect of impaired preconscious processing and integration at level 2, I present the example of my cat. Some may object to linking cat behaviour to autism, however many autistics argue they share similar traits (WrongPlanet.net, 2012a). Other autistic writers also identify with animals Prince Hughes with gorillas and Grandin discusses correspondences between autistic and animal demeanours (Grandin and Johnson, 2005; Prince-Hughes, 2004:3).

At level I, the basic level of processing, through habit my cat knows when I stop typing I go and lie on the sofa. She follows, jumping up, expecting to be stroked. Her processing is fine as far as it goes, but what she cannot do is level two, preconsciously reading that I am tired, not wanting her to jump up and paddle my arm with her paws. My cat cannot work out from my body language i.e. lying arms crossed, eyes closed, that I want to be left alone. In a similar way, many autistics cannot process these social and spatial cues or use logic to create strategies at level 3 to read and react to them. Whereas the typically developing population would instinctively read that I did not want to be disturbed from my body language. However, few would be able to describe how they came to this conclusion as this is largely preconscious.

Using logic to compensate for differences in preconscious processing at level 2 is a strategy used by many autistics to create semantic rules. However, they cannot manage the contingencies of every event. Therefore, in my example the postal worker may knock on my door wanting a signature for a parcel. However, the autistic person having created a rule that I must not be disturbed when I am lying on the sofa might tell the postal worker I could not sign for it. This would annoy me, as I would

have to collect it from post office. This brief example shows the complexity of social and spatial cues makes it impossible for logic-based rules to deal with the nuances of every situation, hence autistics are stereotyped as inflexible and socially awkward (Geurts et al., 2009:75; Howlin et al., 2000:571). Therefore, autistics are not intentionally inflexible but compensating for differences in preconscious processing social and spatial cues.

Ben Shalom argues that only being able to process information at level I and level 3, without being able to integrate it at level 2, creates a constant tension in autistics' minds (Ben Shalom and Clemerson, 2011). Their minds always veer towards level 2, but as they cannot integrate information there, they have to go around it to level 3 or level I, as illustrated in figure 4:

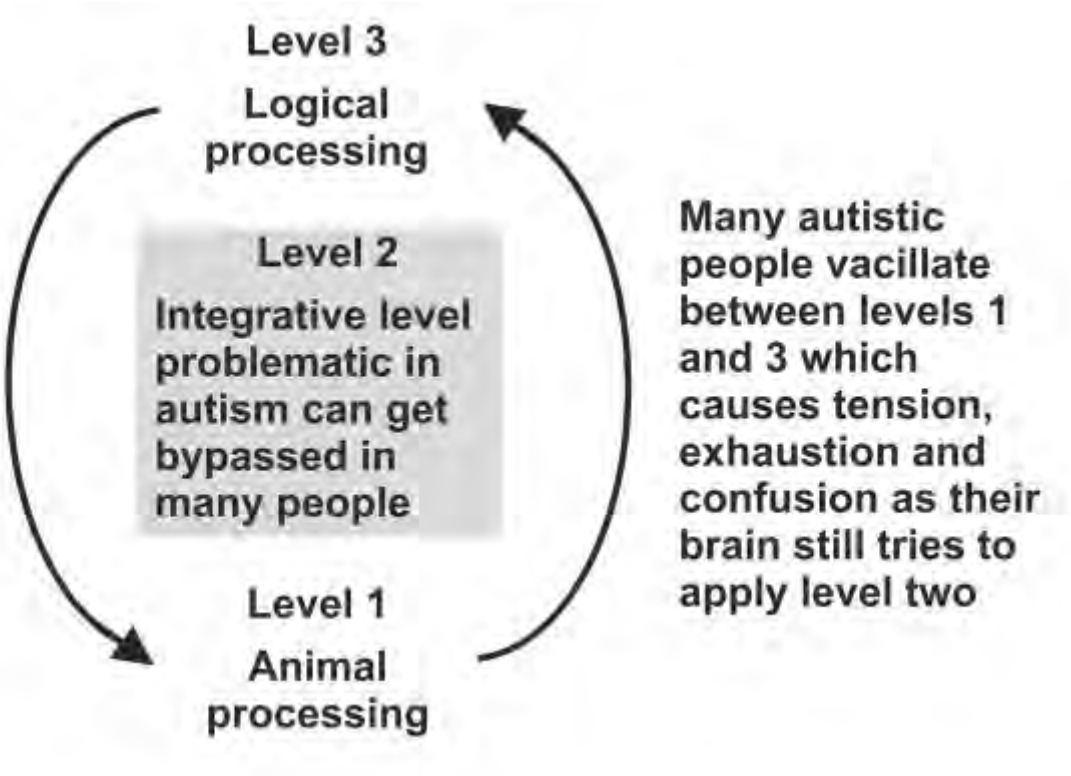

Figure 5. Showing how autistics have a tendency to bypass level 2 as they cannot preconsciously process information at this level (Ben Shalom and Clemerson, 2011)

The tension created by this process was crucial towards my understanding of why many autistics are hyperaroused by their socio-spatial experience.

The four domains

I will now discuss Ben Shalom's application of these levels to four domains, motor, emotion, memory, and sensation/perception. An overview of the domains and the effect of processing at each level is outlined in table 4 below:

Domains	Motor	Emotion	Memory	Sensation/ perception
Level 3 Conscious use of compensatory strategies often based on semantic rules	Logical processing of motor behaviour	Logical processing of the senses	Logical processing of facts - semantic memory	Logical processing of what is being perceived
Level 2 Pre-conscious - most difficult for autistics	Integrative level based on motor planning	Integration of the senses	Integration of memory episodes does not occur until age four (Lind and Bowler, 2008:167)	Integration of perceptual objects
Level 1 Unconscious Animal like processing	A basic level processing of motor control and planning not including motor actions, rote skills	Unconscious sensing	Habit, procedural and perceptual memory	Unconscious perception of perceptually defined parts of objects

Table 4. An overview of the three levels of functioning and their relationship to the full domains (Ben Shalom and Clemerson, 2011)

I now give a brief overview of the main issues in each domain, the effects of which will be discussed in detail within each case narrative and analysis.

Motor

The most important impact on the spatial functioning of those affected is lack of preconscious ability to plan motor actions at level 2. This means that they often cannot read the motor actions of others or use body language, to indicate their motor intentions, for instance when attempting to pass someone on a narrow pathway. Being unable to read the motor actions of others also, means many autistics cannot reciprocate gestures, for instance, use body language to show they understand, approve of, or agree.

Explanations for differences in preconscious processing are found in the work of other neuroscientists. Courchesne and Pierce (2005) and Belmonte et al (2004b) state that neural networks in the autistic brain are in states of over and under connection most of the time (Belmonte et al., 2004b:647; Courchesne and Pierce, 2005:225). Too much connection swamps the signals, and too little leads to them being lost in the noise of over connection. In either case, they argue, large segments of the neural network are either in an all-on or an all-off state, reducing the network's information processing capacity (Belmonte et al., 2004b:647).

Differences in integratory motor planning are also discussed by Hobson, who observes a contradiction between autistics finding difficulty and/or being rarely moved to imitate the actions of others (DeMyer et al., 1972; Rogers et al., 2003 quoted in Hobson, 2010:392), and their ability to copy goal-directed actions (Charman and Baron-Cohen, 1994; Morgan et al., 1989 quoted in Hobson, 2010:392).

Emotion

Emotion at level one is an unconscious physiological response. To use the example of anger, at this level it is clearly evident and difficult for some autistics to modulate (Murray quoted in Burne, 2005; Grandin and Johnson, 2005:92f). At this level self-calming strategies which are partly preconscious, requiring integration at level 2 are not available to modulate the person's anger (Ben Shalom and Clemerson, 2011). I suggest this is why Smith Myles argues that trying to reason with someone when they are having a meltdown is futile (Smith Myles, 2011).

However, the ability to read the emotions of themselves and others did not appear to be totally absent in most of the participants, but rather they rely on different cues. In this context it is important to distinguish between innate physiological emotions as bodily reactions which are relatively intact in autism, while basic and complex, psychological feelings are either atypical or 'impaired' (LeDoux, 1996 quoted in Faran and Ben Shalom, 2008:98). LeDoux states that 'conscious feelings are not required to produce emotional responses, which, like cognitive processes, involve unconscious processing mechanisms' (LeDoux, 2000:156f).

Memory

Until reading Ben Shalom's integrative theory, I did not realise how significant different types of memory are to spatial functioning. She argues that memory operates differently in each of her three levels.

Level 3 Semantic memory

Semantic or long-term memory operates at level 3, it is context free and consists of factual, rules, principles, concepts, knowledge, i.e. 'elephants live in Africa' (Ben

Shalom and Clemerson, 2011; Jordan, 2008:295; Lind and Bowler, 2010:896). For more information on semantic memory look at Gardiner, 2008:8 andToichi, 2008.

As I discussed above autistics use logic at level 3 to understand and meet the expectations of social conventions. In the memory domain, semantic and procedural memory often work together. Procedural memory is used to memorise the steps of a task, for instance how to greet someone, each step of the task cuing the next one. Jordan argues, as I do, that rules created this way may be inflexibly applied, without adapting them to the context.

Level 2 Episodic memory

Inflexible use of procedural memory could be compounded by impaired episodic memory; memory of similar instances in the past to create rules for the current situation (Jordan, 2008:295). Bowler et al, argue that differences in episodic memory can be compensated for to some extent by semantic memory (Bowler et al., 2000:30ff).

Episodic memory refers to personally experienced events (Lind and Bowler, 2010:896). This type of memory is complex bringing together diverse types of information registered in different parts of the brain (Boucher, 2007:256). For those affected by impaired episodic memory, spatially this means not being able to visualise places they have visited before. JS provides a good account of this in Boucher's case study of his memory functioning. He states that despite visiting London regularly he cannot visualise in advance what the airport will look like, relying on spatial elements to remind him of previous visits and where he has to go (Boucher, 2007:256).

Another aspect of episodic memory is the construction of present events out of past ones, for instance, remembering the consequences of past actions so as to repeat or not repeat them. In a similar vein, having no episodic memory makes it difficult to imagine the future (Lind and Bowler, 2010:896)

Differences in episodic memory also mean that many autistic people cannot remember significant life events that create a sense of self such as sporting or academic success, and life passages. Alternatively, they may only remember an event if an intense emotion occurred at the same time. For those affected, not developing a sense of self makes it difficult to develop a persona. Having a persona is important when using space as it creates a physical and psychological presence; having no spatial presence makes you invisible or your body language hard to read, as we will see in some of the case studies.

Level 1 Perceptual or single item memory

This refers to raw, non-declarative, implicit cognitive and perceptual information (Faran and Ben Shalom, 2008:87). Memory at this level relates to simple skills, often learned through habit (Boucher, 2007:261). This form of memory is often very good in autism, as evidenced by savantism (Jordan, 2008:294-295). One reason for this could be that context and item are bound together in the perceptual memory system, therefore they do not have to be preconsciously integrated as episodic memory does (Faran and Ben Shalom, 2008:87).

Sensation/perception

Relating to sensation and perception, the most important differences are found in those who are Ben Shalom's type I. They perceive the world at level I, through unconscious perception of perceptually defined parts of objects, such as in the

example I gave of Williams's doll's house. Because she could not preconsciously unify the doll's house at level 2, her main interest was in the parts, which formed coherent objects that she sorted according to shape, rather than perceiving the unified object and its function (Williams, 1998:20). Typically developing people would have automatically seen a doll's house rather than its parts, because they seamlessly, preconsciously integrate the parts at level 2. Those autistics with disunified vision have to consciously assemble the parts using logic at level 3. As we shall see in Chapter 4, this has important implications for object recognition and use, and spatial processing.

Autistics not able to keep up with the pace of socio-spatial interaction

From my discussion of the three levels of functioning and their application to each of the four domains, autistics' spatial issues, become apparent. The most significant is the effect of differences in preconscious processing at level 2.

These issues are also discussed by Gepner, who coined the term Temporo-Spatial Processing Disorder, which he argues manifests in autism as abnormalities in perceiving and integrating rapid and transient occurrences. These include rapid physical and facial movements, speech flow, and proprioceptive inputs, which all involve preconscious processing.

Gepner suggests difficulties in this area result in differences in sensory-motor coupling, motor anticipation, inhibitory control and executive function, as well as language abilities resulting in slowed and delayed motor and cognitive actions. He argues that failure in rapidly processing sensory events results in differences in

perception, imitation, perceiving, understanding and producing emotional and verbal events on time (Gepner, 2004:1227).

Crane et al found differences in sensory processing in 94.4% of their autistic sample, each having very different, yet similarly severe, sensory processing abnormalities, suggesting unusual sensory processing extends across the lifespan (Crane et al., 2009).

These are crucial observations in understanding autistics' spatial concerns as presented through case studies in the following chapters.

Section 2: Space

In this section, I chart the development of the analytical framework for space in this study to show that autistic spatial experience extends beyond its physical, aesthetic, or even sensory aspects. In doing this I present the theories from human geography, environmental psychology, sociology, and anthropology that broadened my conception of space to understand the experience of participants in this study. This leads the discussion of space beyond its material existence in the form of buildings, cities, and landscapes that are traditionally seen as separate from the human body apart from dimensional and aesthetic appreciation. I use the framework for this study to suggest the body and the space surrounding it are interrelated on many levels, constituting the flow of daily experience. This interrelated flow contains many seen and unseen spatial and social cues, which Gepner and Ben Shalom suggest many autistics have difficulty integrating and responding to fast enough (Ben Shalom, 2009:589ff; Cresswell, 2004:39; Gepner, 2004:1227; Tuan, 2008:3).

Abstract versus lived space

Firstly, I will clarify what I want to find out from autistics about space in relation to their perception and functioning in it and what makes this problematic. This is not primarily concerned with discovering their constructions or interpretations of space; what they think of the countryside, the town or certain types of architecture, or how these make them feel. These discussions are abstract, cognitive, and intellectual, removed from the specifics of autistics' daily spatial experience, thereby largely beyond the scope of this study. I do not want to risk 'knowing' everything about theories of space, but nothing about the experience of its users. My aim has been to gain a broader, functional, and social understanding of autistics' interaction with

space to inform policy and legislation regarding their spatial requirements. Often theoretical discussions concerning the interpretation and construction of space discuss it as an abstract external entity, whereas for many participants in this study space is a functional, social, internally and externally connected reality. What is happening in the space of the body is often as important or supersedes what is occurring in the space outside it. For many perception of space is through the functioning of the body, as a continually, consciously experienced, monitored and controlled, whereas in the typically developing these are mainly seamlessly occurring, preconscious processes.

Arguing on similar lines, Merleau-Ponty argues that the body rather than the mind is the central organ in the perception of space (Merleau-Ponty, 2002:239). Similarly, Knoblich stresses the importance of perception and action in cognition (Hommel, Muesseler, Aschersleben, & Prinz, 2001; Prinz, 1997 quoted in Knoblich, 2008:44). Therefore, Merleau-Ponty argues that intellectualism and empiricism do not give us an account of the human experience of the world (Merleau-Ponty, 2002:298). The other concern is the temptation for intellectualised interpretations or constructions to become mine rather than the participants', distorting the data and perpetuating the distance between the participant's reality and my own. Additionally, solely focusing on how autistics conceptualise space or what they think of it would slide round the central imperative of the study, to understand autistic people's perceptions of and functioning in space and what makes this problematic; only partially answering the question. I might discover what autistics think of space, but not how they experience it daily. Granek and her team describe being diverted by existing theory during their research of women's experience of depression. They found the women always discussed their relationships even when redirected. From this they realised they had

erroneously separated the women's depression from the context of their daily lives (Granek, 2011:2). Applying Granek's experience to this research, attempting to describe how autistics' construct or interpret space, a popular one is like being on another planet, or that space is sensorially and socially overwhelming, hostile and/or frustrating. Although useful as starting points these are limited to what autistics think about space but not what is happening when they are in it, which is the aim of this study.

Accordingly, I have shaped the analytical framework for this study to focus on understanding autistics' moment-to-moment, daily experience of space. This includes taking into account Merleau-Ponty's argument using the example of vision, based on the experiments of GM Stratton, that we 'spatialize' space and the objects in it using perception as an unconscious process, which is not accessible, even significantly in the generally accepted sense (Merleau-Ponty, 2002:284ff; Merleau-Ponty and Davis, 2004:39). This argument illustrates the limitations of brain-based cognition and theory in relation to space.

Therefore, I conclude that traditional, abstract, aesthetic constructions and interpretations of space are too distanced and general for this study; which investigates relational and immediate two-way flows between bodily perceptions of space and space itself. These go beyond popular, abstract perceptions of space which when it is discussed at all, are limited to its visual, physical, aesthetic, and dimensional properties such as architectural styles, buildings, roads and landscape features. This rarely encompasses the detail of the daily flow of relational, spatial experience, effectively silencing the users' perspective (Seamon and Sowers, 2009:

introduction). I hope to overcome this by applying a broader conception of space and spatial experience to this study,

I suggest that popular, traditional, abstract conceptions of space equate to a positivistic view, following a similar pattern to that of the medical model, both models decontextualizing and thereby divorcing space and autism from daily life (Seamon and Sowers, 2009: introduction). For instance the application of Euclidean geometry and the influence of Le Corbusier's modular ('normal') man to design assuming this will meet the requirements of all (Imrie, 1999:48; Lefebvre, 1991:48). The analytical framework for this study moves away from these abstractions and generalisations to the detail of autistics' daily spatial experience.

Wishing to frame space contextually in real-time rather theoretically led me to Massey's work, she also argues space is moving and contingent, not abstract and static (Massey, 2005:130). From Massey's argument, I conclude that it is not possible to theoretically or otherwise 'fix' autism, space, and the relationship between the two, as they are fluid and subjective and therefore can only be tentatively understood as part of a continuum.

As such, developing constructions or interpretations of space would limit this study to providing professionals, policymakers, and those sharing autistic people's lives with yet more obscure research, generalising autistic spatial experience. I suggest this would lead 'tick box' design and policy development, rather detailed context dependent designs and policies, focused on the requirements of end-users. Instead, I wish the findings of this study to be used to tentatively to inform initial dialogue with autistic individuals or groups, to designing according to their requirements and context. Following this line of thought, this study makes no claim to being definitive

or comprehensive, but part of an on-going reflective, ethical, relational, dialogue, that responds to the changing demands of autistics' spatial requirements.

Space as a flow of experience

Having clarified the aspects of space focused on in this study and the reasons for it, I will now discuss the theories that informed the analytical framework of space in this study. Thinking about the body and its relationship to space drew me to Thrift's work. He describes the body rather than the mind as being interwoven with space, creating the notion of space as a fluid, seen and unseen phenomenon (Thrift, 2008:62). Using the example of rock climbing he argues the body and space relate on multiple levels through a 'distributed cognitive system', in which 'thinking' is done through interaction between human and spatial processes such as gravitation (Hales 290, 1999 quoted in Thrift, 2008:160). This enables climbers to 'flow' up peaks, bodily hypersensitivity to gravity responding to the terrain, as its pull fluctuates with their line of travel (Kwinter 2001 quoted in Thrift, 2008:12).

From this, I began to understand space as a flow of experience and relations between its physical, functional, ascetic, ideological, and social elements. These then intertwine with sensory, physiological, visceral, cognitive, and psychological experience of the body as a space within space. Therefore I propose in this study these processes flow together, cognition of space taking place in mind and body simultaneously, flowing together on a largely 'unseen', temporal continuum. For typically developing people in familiar environments, responding to unseen processes is preconscious and relatively unproblematic, obscuring their complexity. However, autistics' accounts and the work of Gepner and Féron, and Ben Shalom indicate this is not so for many autistics (Gepner and Féron, 2009:1227).

These shifting, nebulous and relational aspects of space mean what we ‘see’ is only a small element of space (Lefebvre, 1991:49). In a school we may see desks, chairs, whiteboard, computers, the work of the students, however this does not tell us how the space ‘affects’ those who use it or how they read and manage their response to the space to meet its social and spatial expectations. This is problematic for many autistics, graphically described by Gerland and Holliday Willey and illustrated in the case studies and (Gerland, 1997:88ff; Holliday Willey, 1999:19ff).

To widen my understanding of space in relation to these issues, I returned to Massey’s work, her fluid conception of space resonating with autistics’ difficulties in adjusting fast enough to the demands of space. She argues that ‘space’ or even place is not static or even related to any geographic location, being instead a collection of stories-so-far, determined by what is brought to it, rather than a defined, physical entity (Massey, 2005:130). From this Massey concludes that daily spatial experience is an indeterminate summation of all our connections, a similar argument to that of Heft (Heft, 2007:85; Massey, 2005:185). Figure 6, on the next page is computer-generated model of the brain, which I use as a metaphor to illustrate space as a summation of all our connections, including the multiple connections of space.

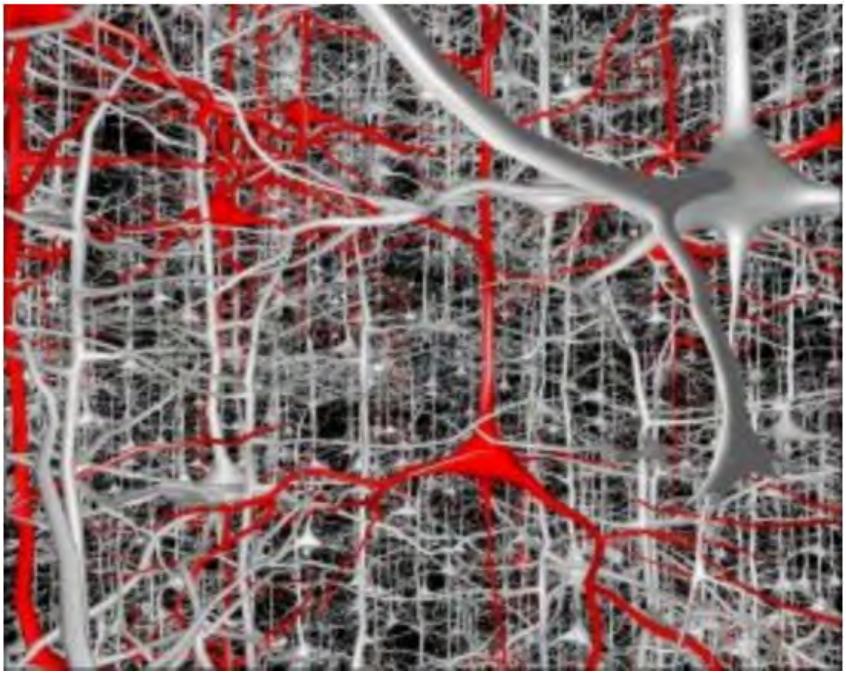

Figure 6. This picture is of a computer-generated model of the brain, which I use as a metaphor to illustrate space as a summation of all our connections including the multiple connections of space. Photo: Brain Mind Institute, EPFL Lausanne

Massey's idea that people bring different sensations, ideologies and ways of being to space (Massey, 2005:12f) drew me to Deleuze's Plane of Immanence, which brings together the spatial, social and ideological; he argues:

> A life is everywhere, in all the moments that a given living subject goes through and that are measured by given lived objects; an immanent life carrying with it the events and singularities that are merely actualized in subjects and objects. (Deleuze and Boyman, 2001:29)

Like Massey he also argues, space consists of the human and ideological elements we bring to it, who we are; expectations and assumptions shaped by our culture, socio-economic status, age, education, physical and mental ability and so on (Deleuze and Boyman, 2001:30). These often shape our preconscious conceptions of how the spaces of daily life should 'be' and the social demeanours we present and

expect in return. Habermas argues that humans are socialised from birth to an internal conception of 'public' space, as essentially social beings (Habermas, 2008:3). Here public is used, both as applied to space, and in the sense of social interaction with others. Demeanour depends on whom we interact with and where: each person and space presenting complex social cues to guide interaction. Even a single space can present different spatial expectations depending on the group or individual being relating to. The student in a classroom will behave in one way towards a teacher and another to peers. A room used for an English class will have very different expectations to one used for an exam. This suggests that space is contextual, social and ideological, not just physical, functional or aesthetic, nearly all space being designed for social and economic purposes (Lefebvre, 1991). Understanding the role of the 'plane' of conscious and preconscious expectations we bring to space is crucial to understanding our spatial expectations and the assumptions we make when they are not met.

The visible body

A major aspect of our 'plane' of expectations is based on the appearance of those around us; this and body language playing a crucial role in the spatial comfort of the individual and those they share space with. Shilling argues bodily appearance, shapes and facilitates social interaction directly determining judgements regarding the person's value and character. He suggests these are linked to a moral imperative to work hard to shape the body, as a reflection of socio-economic status and values (Shilling, 2010:8,11). These cue those around them to the demeanour the person is likely to present and expect in return from those sharing space with them. The significance of this is highlighted in the concern over Muslim women wishing to keep their faces covered, relating not only to identification but also to inability to read their

facial expression. Other examples are the difference between someone behaving angrily or reassuringly or a group of young men in hooded T-shirts, compared to them in business dress for instance. This is problematic for some of the participants in this study, as their appearance is ambiguous. This can create a sense of incongruity, often providing little clue as to their social status, sometimes even their age, complicated by the absence of/or partial presentation of expected bodily demeanour. This is complicated, as some of the case studies show, when typically developing people cannot quite quantify what is different about the autistic person. This causes more tension than when they can understand what is different about their presentation and associated demeanours.

Goffman discusses the central role of appearance and body language, arguing there is an obligation to convey or not convey information, through body language, such as friendliness or hostility, when in the presence of others, even when silent, congruent with the person's socio-economic status (Goffman, 1966:35). He suggests this process, in a similar way to Deleuze's Plane of Immanence, is a largely unconscious, expressive, common idiom, made up of a vocabulary of body symbols, which most people have access to (Deleuze and Boyman, 2001:29; Goffman, 1966:35). However, the participants in this study show that pre-conscious processing to read and respond correctly to others body language is slower or different, due for instance to disunified vision, the sensory effects of space or difficulty reading spatial cues. Some of these issues are listed in figure 7 below:

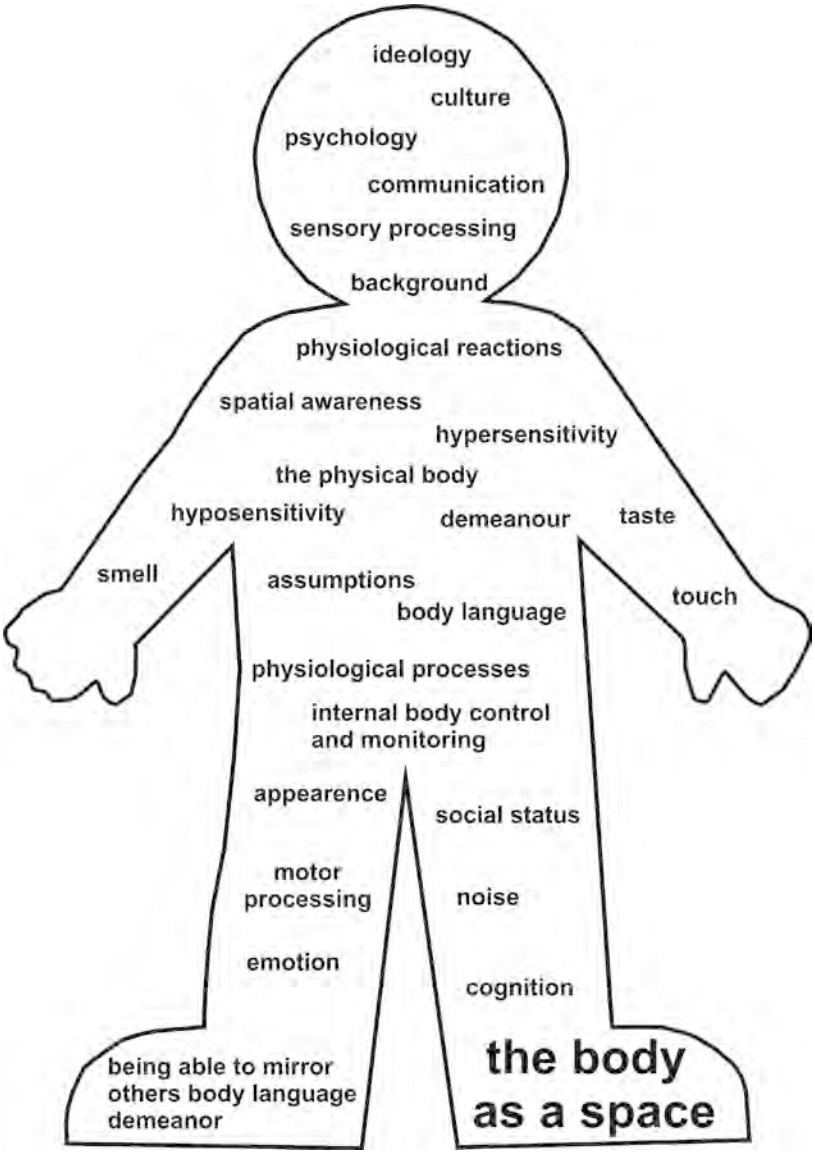

Figure 7. Issues affecting the space of the body

These concerns are further complicated for those who have issues with body awareness; Tito Mukhopadhyay describes his body as scattered. This affects some autistics' ability to respond to other's movements such as when passing on a footpath or through a doorway, which will be discussed in greater detail in the case studies (Mukhopadhyay, 2000:20).

The unseen body - affect

Staying with the body, but continuing to move the focus away from mind based cognition as the sole interpreter of space, I now link internal spatial processing to the spatial concept of affect. Thrift states that affect is a different kind of intelligence about the world, a form of thinking and thought in action that shapes people and space (Thrift, 2004:60; Thrift, 2008:175). Going back to his example of a rock climber he suggests that that not only does the climber play their part by mastering gravity, but the mountain in turn provides crevices that allow the climber to navigate it (Thrift, 2008:11). Therefore he argues that a different kind of intelligence or sensing of, and with the world is taking place, not considered in traditional perceptions of space (Thrift, 2004:60). This alternative sensing of the world is also discussed by Heft, who terms it 'perceiver-environment interaction' (Heft, 2003:151). Franck and Lepori arguing along similar lines suggest that ‘bodies are porous, permeable, deeply connected with their surroundings and with others and by themselves incomplete’ (Franck and Lepori, 2007:48).

Corresponding with these views Massumi argues for bodily rather than mind-based cognition of space. He discusses the senses in a parallel way to Massey's discussion of space, highlighting their complexity and interrelatedness. Using vision as an example, he argues that its purpose is not only to see space, but is also synesthetic and kinaesthetic, combining with proprioception to aid navigation through habit rather than mind-based cognition (Massumi, 1998:16). In doing so Massumi questions the centrality of mind-based cognition, suggesting instead that experience is mediated through the body as a spatially located form related to its surroundings (Massumi, 1998:16). Therefore he argues life is on the surface of movement, rather than in the mind, forms being perceived externally from within in our stream of experience,

somewhat in line with Ben Shalom's preconscious processing (Ben Shalom and Clemerson, 2011; Massumi, 1998:16). An example of this is cycling, if you turn the corner looking ahead to where you are going, you go round smoothly, if you focus on the corner itself using logic it is much more difficult. For most of us these complex processes pass us by, until age or a neurological condition bring them to our attention. For many autistic people their spatial experience is a central aspect of their daily lives, often managed consciously, rather than as with typically developing people, being a predominantly preconscious process based on intuitive responses (Ben Shalom and Clemerson, 2011). However, as Massumi describes this is often a physiological or visceral process rather than a cognitively dominated one. Arguing in a similar vein, Shiffrar and her colleagues argue in their research using light-point displays, against the view that vision is the only way human movement is analysed, for instance when negotiating the way past someone on a narrow path. Instead they argue that the analysis of movement depends on a convergence of motor planning, perceptual learning and social, emotional processing (Shiffrar, 2008:114).

Cognition as embodiment

This leads us to the work of Thelen, who rejects brain-based conceptions of a knowable world, consisting of formal systems of symbols, logic, and computation (Thelen, 1995:74). She argues that this denies the role of the physical body in the understanding of space through movement, feeling, and emotion, following a similar line to that of Thrift, Massumi and Shiffrar (Thelen, 1995:74).

Instead, Thelen argues for a dynamic model of cognition derived from bodily interaction with the world (Thelen, 1995:74). Thelen and her colleagues argue like Shiffrar, that cognition is inseparably linked with perceptual and motor capabilities

that mesh with reasoning, memory, emotion, language, and all other aspects of mental life (Thelen et al., 2001:1). Aligned with this view, Miles et al's recent research into mental time travel, argues that it is grounded in perception-action systems that support social-cognitive functioning. They found that time and space are embodied, those in the study moving their bodies backwards and forwards in the direction of the aspect of time travel they were talking about, as part of an otherwise invisible mental operation (Miles et al., 2010:223). The perception of brain-based at the expense of embodied cognition, could account for the predominance of the visual in spatial design, and the goal rather than process focused nature of much autism research. I suggest Thelen’s argument provides compelling justification for researching autistic experience through a relational, contextual, and qualitative research method such as go-along interviews.

From a combination of autistic authored accounts and my analytical framework for autism and space so far I have developed the diagram in figure 8 on the next page, to illustrate my understanding of the complexity of autistic spatial experience at this point:

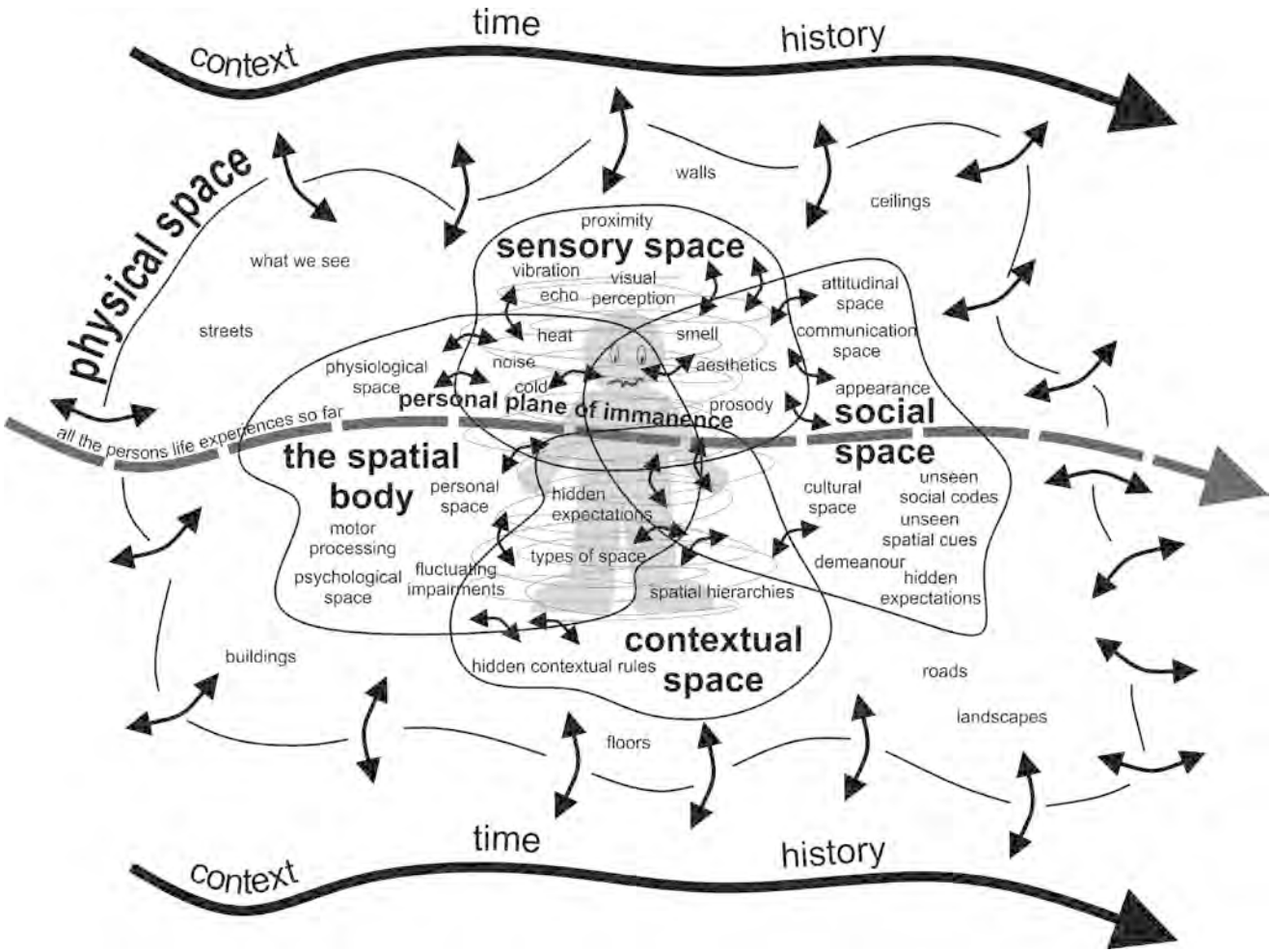

Figure 8. My conception of space developed from my analytical framework for space so far, illustrating the fluid and in process nature of space including that of the body.

From this diagram, I conclude that for many autistic people space is intrusive, insistent, and unrelenting, demanding an immediate fluid and flexible response, to multiple, simultaneously occurring stimuli, and often hidden spatial and social cues.

Hidden spatial and social cues

These are often the most problematic aspects of autistics' spatial interaction because they require a rapid and correct response as non-compliance often leads to negative assumptions. Difficulty responding to what I come to term socio-spatial cues, to indicate their interrelated nature, is slowed or absent for many autistics due to lack of integration of spatial information at Ben Shalom's level 2, compensated for by use of logic at level 3, to develop rules for spatial interaction. Social rules created using logic are often not flexible enough to meet the nuances of every situation, hence the ascription of rigidity of thinking to autistics. Understood this way, rigidity makes sense as a legitimate difference in functioning, rather than lack of ability or intransigence. Slowed, sometimes stilted responses means that autistics are often perceived as out of step with those around them, causing frustrations and misunderstandings (Gepner and Féron, 2009:1227).

Rapoport argues hidden, ideologically informed social and spatial cues of space, are inculcated and perpetuated through the design process, illustrated in figure 9 adapted from his work (Rapoport, 1994:69; Sapir, 1927a:137).

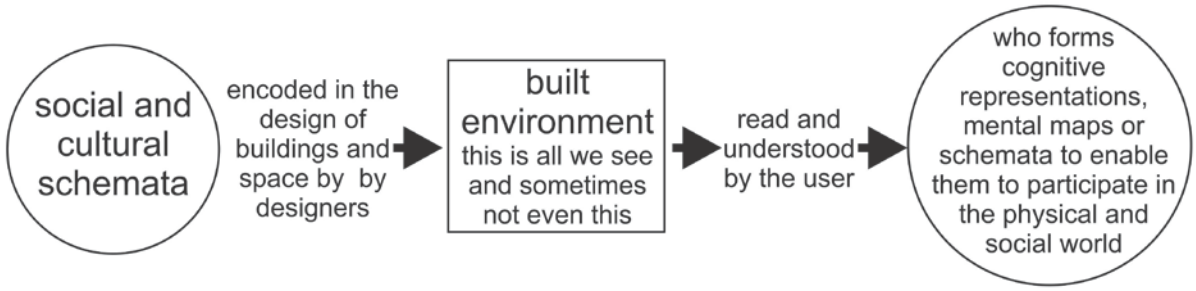

Figure 9. After Rapoport: illustrating how unseen cultural codes come to be embedded in the environment (Rapoport, 1994:69).

He argues physical design forms only a small part of spatial design, the most important being the unseen aspects of space. Rapoport suggest these act to prompt specific behaviours in each context, to create cohesive interaction (Rapoport, 1994:70,72f). Similarly Franck and Lepori argue that space is designed to encourage certain behaviours and attitudes, whilst forcefully discouraging others (Franck and Lepori, 2007:52). This is illustrated by Andrews et al, investigating the spatial processes of a body building gym; for instance cues to prevent monopolisation of equipment or the slowing down of training schedules by those wishing to socialise (Andrews et al., 2005:882ff).

Barker discusses the role of space in social control in his study of the American Midwest; in what he terms 'behaviour settings' (Barker, 1968:18f). He suggest each setting has its own complex rules, which constrain each other; how these work is often not obvious to outsiders (Barker, 1963:20). Thrift, employs Vesely's concept of the 'latent world' to similarly argue the existence of well structured, significant influences on the visual world (Vesely quoted in Thrift, 2004:16).

Habermas states these hidden social rules are learnt through socialisation, the individuals' internal space becoming a reflection of, public space which is lived simultaneously internally and externally (Habermas, 2008:3). Although Habermas's

focus is on discourse, here I apply his theories to personal, spatial interaction. He argues that our interactions depend on reciprocity, entangling individual in ever denser and more fragile networks of relationships, exposing individuals to the possibility that reciprocity may be denied (Habermas, 2008:5). Applied to this study, this can happen between typically developing and autistics when they fail to participate precisely in discourse according to 'universal, worldwide norms of action' (Habermas, 2008:6).

Moving away from discourse, while maintaining a focus on social and spatial cues leads us to Giddens and Sapir, who discuss the social implications of preconscious social cues that are essential to social and spatial functioning (Giddens, 1984:4; Sapir, 1927b:137). Sapir argues many cultural norms operate

> '…in accordance with an elaborate and secret code that is written nowhere, known by none and understood by all.' (Sapir, 1927b:137)

Bourdieu adds to the argument, stating that habit rather than necessity perpetuates these rules (Bourdieu, 1989; Bourdieu and Nice, 1977:72; Sapir, 1927b:121). When reading the case studies, you will see how difficult these elusive, self-perpetuating, unseen social and spatial cues are for autistics to comprehend and comply with. In turn as these cultural cues are often preconscious, and intuitively carried out they are difficult for typically developing people to explain to autistics.

Goffman argues that we live in a world of social encounters and adherence to social and spatial cues is vital for social interaction (Goffman, 1972:5). Mondada suggests social interaction is contextualised, situated within the material and spatial environment rather than individuated (Mondada, 2011:150). Therefore I argue that

interaction always happens somewhere and 'somewhere' always has a context with associated social and spatial expectations of demeanour determined by the ideology and context of the exchange. Goffman suggests each episode of 'talk' places the participants in a spontaneous, mystical social space with a life of its own, having its' own demands and boundaries (Goffman, 1957:47). Along these lines Creswell suggests space is constructed through reiterative social/spatial performance and practice. de Certeau describes it as a practiced place, transformed into space by those who use it, with its own system of signs (Cresswell, 2004:39; de Certeau, 1988:117). Following the same argument, Soja states that social reality is not coincidently spatial, but is inherently so. He argues that there is no 'unspatialised' social reality or aspatial processes, even in the realm of the abstract, most processes being spatialised (Soja, 1998:46).

The sum of these arguments contributes to the analytical framework for space in this study, which argues that social interaction is inherently spatial, whether in real-time, virtual or written occurring in what I, along with Lefebvre terms 'social space' (Lefebvre, 1991:33). In this study this refers to the immediate space of communication between one or more people with its own expectations determined by the ideology and context of the culture of its physical location. This space contains material and human objects that project stimuli into the space according to its seen and unseen socio spatial codes with their associated expectations and assumptions made regarding non-compliance. Some might argue this is not a space. However, consider a restaurant, one table might contain a group of students, another mothers and babies and another a business meeting. Each table forms a space with its own culture and expectations of demeanour and topics to be discussed, forming its own social space within the same physical space.

A further argument against the denial of the existence of social space is that by denying its existence, and suggesting this study only discusses autistics' communication issues, personalises their issues. This I suggest would return us to the medical model of disability, which argues it is up to disabled people to overcome their impairments, instead of recognising the effect of socialy created barriers argued by the social model of disability which underpins UK policy and legislation (DRC, 2005; National Audit Office, 2009b:4,11). Ignoring the existence and implications of social space would shut off a spatial and socially situated understanding of autistic people's daily lives including their interaction with others. However, human communication is demonstrated by this study to not be limited to talk or interpersonal dynamics, but a complicated, socially and spatially located exchange of intricate cues that make it problematic for autistic and other groups of people who are not part of the dominant culture.

From the discussion of space in my analytical framework so far, my conclusion is that space is constantly in motion, the body also being a space in its own right with its own physiological and psychological processes, integrated into the space surrounding it. This space is shaped by the cultural ideology and context of its geographical location, which in turn is shaped by the life experiences so far of those who enter it, shaping their expectations of the space and their assumptions regarding those who do not conform. This establishes space in this study firmly within the everyday rather than as an abstract, dimensional, visual, aesthetic entity.

An important aspect of the everyday is human spatial interaction, the discussion of which is largely divorced from its spatial context, even in Goffman's work, there being an apparent divide between the disciplines of sociology, environmental sciences and

the built environment professions. Thrift and Massey's accounts of space, as in process, inherently social and embodied come close, but still stand outside spatially located person-to-person encounters.

Existing typologies of space

Attempts to understand the spatial situatedness of humans within their social network have been made by several theorists. Bronfenbrenner created ecological systems theory to explain children's developmental environment as illustrated in figure 10 below:

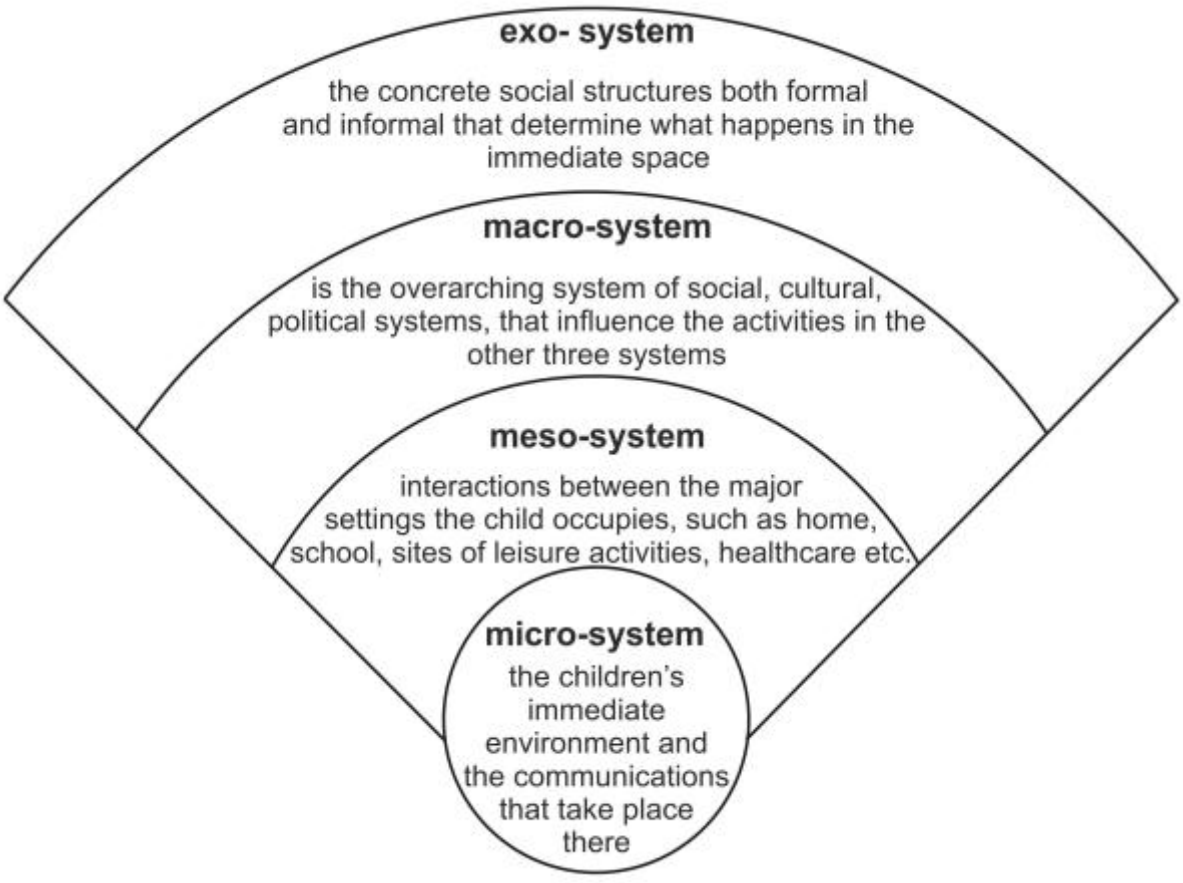

Figure 10. Bronfenbrenner's ecological systems theory (Bronfenbrenner, 1976:5)

This is further developed in Smith's work. He shows the amalgamation of physical and social space, experienced by students in school classrooms, illustrated in figure 11 below.

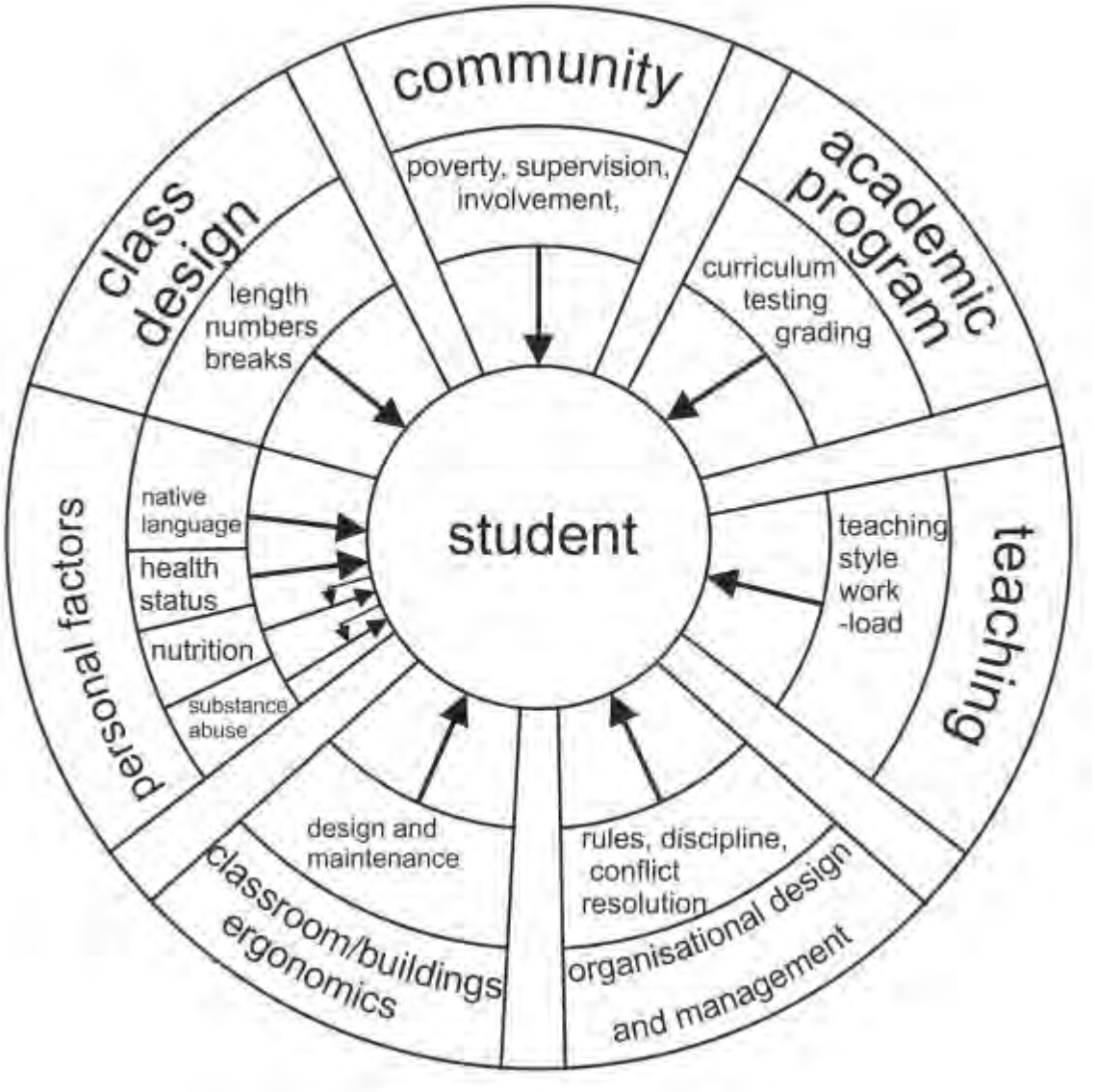

Figure 11. Source: Smith (2007) showing the interrelatedness of the social, physical and ideological aspects of space.

This is the basis for the hexagon spindle model of space used by Woodcock et al to illustrate the processes shaping learning environments used by autistic children (Smith, 2007:1536; Woodcock et al., 2009:251).

However, what Smith, Bronfenbrenner and Woodcock et al's models do not do is illustrate what happens in the middle space, during the interaction between the students and others around them and how this affects their functioning and why. This is crucial to understanding autistic people's perception of functioning in space and why this is problematic. Therefore despite my reservations regarding theory, I decided to create my own typology to fill the gap, partially based on Bronfenbrenner's model.

A new typology of space

Social space

First one could argue my view of what space is is too all encompasing. My answer is that space surrounds us from the universe down, through planetary systems, the world to the specifics of the spaces that contain our daily lives. My typology suggests these are inherently social. With five main elements, the ideological, contextual, interactional, personal and the body as space, illustrated in figure 12 below:

Figure 12. Social space showing the of elements of space, that I suggest constitute social space

I will now describe each of the elements in detail showing how they relate to each other.

Ideological

Ideological elements are largely culturally determined, their influence often, at least partially visible in the aesthetics and design of space. However, ideology is often also the major determinant of invisible social and spatial cues that determine behaviour, expectations, and assumptions. These also shape the life experiences,

expectations and assumptions of the people entering and participating in the space, an example could be a British office.

Contextual

Contextual elements including the sensory are largely geographically determined. Using the example of a British office, it may house a legal practice which is influenced by the culture of that profession (ideological element) which in turn is shaped by its local context. The expectations of the legal office in central London may be very different from one in a seaside town. Due to land values in central London the office maybe open plan and the seaside town individual offices. Each having different effects on sensory and social processing. Therefore the contextual element of social space is influenced in this case by the ideology of Britishness, of the legal profession and its geographic location.

Interactional

Ideological and contextual elements combine to shape the seen and unseen social and spatial cues which determine the interactional elements of that space. This includes expectations of demeanour and the assumptions made when they are not adhered to. As I have argued already these hidden social and spatial cues are the most difficult for many autistics to read and respond to.

Personal space

Autistics and those they share space with, may feel each negatively breaches the others' personal space. Autistics may find the noise, smell and social demands of typically developing people too much, for instance harsh verbal intonation, strong perfume and expectations to make small talk. Typically developing people on the other hand may feel vulnerable around autistic people, not knowing how to respond

to those who are unable to modulate their emotions, loudness of speech, impinging on both's ability to preserve the spatial status quo.

The body as space

The space of the body often impinges on functioning in social space. Many autistics are acutely aware of their bodily processes as their body often does not respond consistently. This is because they cannot integrate their bodily processing preconsciously therefore they have to attempt to consciously monitor and manage bodily processes such as temperature, motor planning and sensory processing and integration.

In conclusion, two important aspects come from the development of my analytical framework as a whole in relation to space; firstly, that social space is a legitimate space in its own right and hot one that is most problematic for autistic people to navigate. Secondly, I conceive the design of space for autistics as being committed to wider and more elusive goals, than merely manipulating the appearance of the built environment and subtlety enforcing social codes. These include ideologically informed and socially motivated goals to promote sociability, difference, inclusion and spatial comfort which are not readily translated into design checklists (Henry 2011b). Franck and Lepori argue in a similar vein that we must rethink space and place placing a greater focus on the users' of space, designing from the inside out to meet, their emotional, social and physical requirements (Franck and Lepori, 2007:5).

Section 3: Research frame

From the context of this study, outlined in the introduction, I realised existing research often decontextualizes autistics' experience, compounding stereotypes and marginalisation. I aim to avoid this, by providing a detailed examination of autistics' daily life. However, as the development of my analytical framework shows, the separate entities of autism and space are complex and detailed. This led to my choosing qualitative rather than quantitative research frame as numerically aggregating the data could have lost important nuances. It could also lead to focusing on my questions regarding autistics' perception of functioning in space and what made this problematic. Instead, I wanted to focus on what was happening during the spatial interaction and what autistic people felt was important for others to understand.

This determined my choice of methodology and methods. I begin by discussing my application of case study methodology to this study, followed by an overview of ethical considerations arising from my positionality as a so-called typically developing person. I follow this with a discussion of my attempts to equalise the research relationship and my application of Fine's theory of the hyphen to explore differences between the participants' experience and my own. Finally, I discuss the application of the go-along method, member[10] checking and triangulation to meet the requirements of the participants in the study and ensure its rigour.

[10] Participants checking of the data.

Methodology

Research frame - case study

I am using case study as I quickly realised the participants' accounts of their daily perceptions of space and functioning within it are highly, detailed, nuanced, and subjective, in all cases going beyond sensory issues. This meant digging deeper into areas that sometimes did not, on the surface appear to be relevant. This often led to lengthy discussions during member checking, uncovering obscured, ephemeral, elusive aspects of space that have important impacts on the spatial comfort and/or inclusion of autistics.

It is important to recognise this study cannot, and was never intended to be a comprehensive account of autistic people's experience; instead, it gives accounts of specific events located in certain times and contexts, recognising that experience is both dynamic and situational.

This was essentially a reflexive, non-linear, ethnographic process, to quote Ryle of 'pondering, reflecting, and deliberating', not following any particular course or excluding any information, in order to create 'thick description' (Ryle, 1968: para 6).

The case study research frame allows me to narrate this process keeping much of the detail intact although still subject to the time constraints and word limit of a doctoral study (Simons, 2009 quoted in Thomas, 2011:512). However, as Thomas argues, the application of case study methodology requires careful thought, if the study is not to become a simple account of the lives of, in this case, autistic people, instead of answering of the research question (Thomas, 2011:513).

Therefore, I will now outline my application of Thomas's typology to this study to answer my question by making clear the subject and object of my research. The 'subjects' (sic) being the historical unit being investigated (autistic people) and the object to understand, in his terms 'the circumstances of a subject', i.e. why space is problematic (Thomas, 2011:513). Thomas argues this should be done through an analytical framework, which I have laid out in this chapter. Then he goes on to present a typology of the key elements, he believes lead to rigorous case study methodology. In figure 13 below is my application of his typology to this study:

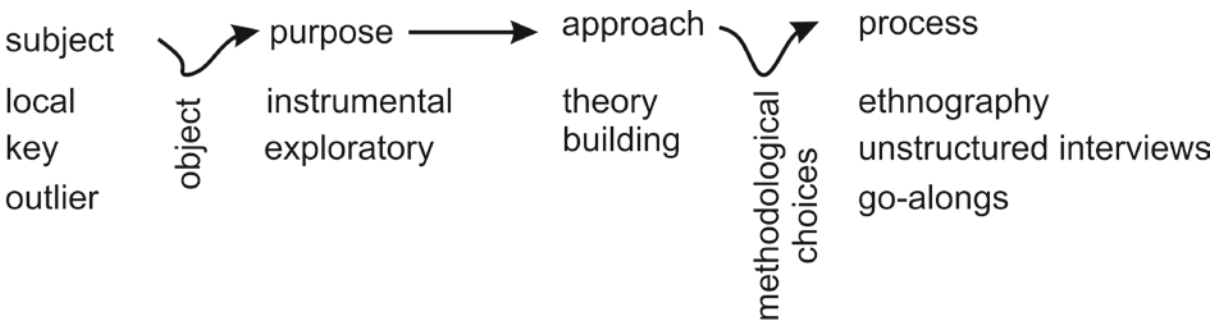

Figure 13: application of Thomas's typology to this study

Returning to the subject. Thomas argues this should be identified as either a local knowledge case, a key case, or an outlier case. This case that of autistics' perception of space and what makes it problematic, I suggest is all three. It is a local knowledge case, based on my experience as a residential and professional social worker, before becoming a landscape architect. These occupations brought me, in hindsight into contact with many undiagnosed autistics, those with learning difficulties, the elderly, single parents, children and young people whose spatial experience is also problematic. It is a key case in that many other groups experience similar socio/spatial and sensory issues, such as those with Alzheimer's, dementia, macular degeneration, ADHD, and schizophrenia, giving this research a wider

relevance (BBC Health, 2012; Javitt, 2009; Miller et al., 2012; Zeisel et al., 2003). Finally, it is an outlier case due to autistic people's perception of and functioning in space being different from the typically developing population.

Moving to the next stage of Thomas's typology, the purpose of this study is instrumental, the aim being to use its findings to inform general policies and those relating to the built and natural environment of autistics' experience and requirements. This study is also exploratory, investigating autistics' perception of and functioning in space and what makes this problematic, through snapshots from multiple cases (Thomas, 2011:518). Here I emphasise again the contingent and transitory nature of space and autism, the snapshots taking place in a particular temporal context within a fluid continuum. Despite the transitory nature of the data it is hoped this study will assist researchers from other disciplines to formulate narrower questions that they may test quantitatively to explore themes raised (Thomas, 2011:515ff).

To return to Thomas's argument that many studies do not clearly articulate important aspects that define them as research rather than mere description. This study does not merely recount events, but analyses them within the context of existing thought in relation to autism and space, outlined in the introduction and the analytical framework of this study presented in this chapter (Thomas, 2011:513). My approach has been ethnographic and interpretive, using unstructured, go-along interviews to relate '…facts and concepts, reality and hypotheses' (Thomas, 2011:515).

Ethics

I would now outline the ethical considerations that run through all aspects of this study. As I indicated earlier, research has historically focused on autism as a disorder, only including autistics as subjects, not participants and certainly not as co-researchers in the research process. This has led many autistics to be sceptical of researchers and the research process. Therefore, my central aim in designing the methodology of this study was to work closely with autistics to avoid objectifying them or decontextualizing their experience and thereby compounding their marginalisation. This would have been both unethical and would have distorted the data. My first concern was to equalise the research relationship as far as possible leading me to Oliver's seminal paper on disability research.

Disability research

In this paper, Oliver argues for the traditional research hierarchy to be replaced with one built '…upon trust and respect and building in participation and reciprocity' (Oliver, 1992:107). Researchers, he says, must study the participants in the context of their daily lives, the research must be of benefit to them and be empowering when the participants decided to empower themselves (Oliver, 1992:109f,111). Oliver also argues that research should be controlled by disabled people (Oliver, 1992:123). Bourne argues researchers should not just, in his case, focus on black people, but should focus on the behaviour of those around them. Applying his assertion to this study, it contextually examines autistic spatial experience, at the same time attempting an equally rigorous examination of the demeanours of those sharing space with autistics, including myself, to illustrate typically developing people's role in their spatial issues (Bourne, 1981 quoted in Oliver, 1992:112). This examination is not restricted to overt 'disablism', or even underlying institutional disablism, but to

reveal subtle, preconscious aspects of both autistic and typically developing people's reading of each other and space to fulfil or not unwritten socio-spatial expectations. To return to disability research, it is also informed by feminist research, taking me to Oakley's seminal study with pregnant women, which provides a comprehensive discussion of the research/participant relationship (Oakley, 1993:ch 17).

Following this, I looked at research carried out with other groups of disabled people, particularly those whose social demeanour is perceived as different. This led to Beresford's and others' discussion of the development of user-led focus groups often used in research with survivors of the mental health system[11] (Beresford, 2007; Faulkner, 2002). This led to me looking at how I could adapt this method to working with autistics.

From these considerations, I determined my choice of research methods, the aim being to fulfil the following criteria:

- The researcher/participant hierarchy should be equalised as far as possible
- The research process should be led by the participants on their terms, at their pace, viewing the world through their 'glasses'
- It should examine autistic socio-spatial perceptions and interactions in the context of their daily lives
- It should improve the lives of autistic people, contributing to their goals and aspirations

[11] This is the term preferred by many people in the United Kingdom who have been long-term users of the psychiatric services

The meeting of these criteria runs through the entire study, focusing on gaining an open-ended understanding of autistics' spatial experience. This required on-going consideration of the research relationship and its effect on data gathering and analysis.

Anonymity

Participation was anonymous apart from, Debra who requested not to be anonymised, as Bearsac, her diagnosis of Asperger's and other activities are well documented through YouTube, Bearsac's website and in her book *Travels with My Teddy Bear* (Schiman, 2009). Initially I took the view that it was up to the participants to choose whether they wished to be anonymous or not. However, I came across someone who had agreed to their name and personal details being made public. In spite of this they were distressed by the reality of their personal details in print. I also take on board that few autistic people are personally credited with their contribution to research and the debate concerning this (Kalen, 2011). Despite anonymity, one person, due to the sensitive nature of their data withdrew parts of it. Member checking, which I discuss in detail further on, was also crucial to gaining people's on-going consent to their data being used, and their understanding of the overall aims of the research.

Positionality/Researcher's role

Member checking was also essential to meet my central objective of attuning to the participants' experience. However, I was concerned when I began my research and throughout that the culturally inherent, negative attitudes to disabled people in society and therefore in me would distort the data. This led to the close examination of my positionality outlined in the introduction. I was not so concerned about being

overtly disableist, but afraid of what Kumari Campbell describes as subtle, socially ingrained, 'business as usual ableism' subconsciously present in everyone; we are aware intellectually we should not be prejudiced, but we instinctively are in many subtle ways (Kumari Campbell, 2008:152).

Research relationship

To overcome this, throughout this study I have focused on creating as equal a relationship with the participants as possible. You will note throughout the thesis, apart from my analytical framework, I discuss the study in the third person. Maintaining momentum and recording the findings and analysis has been *mine*, but the experiences and analysis are collaborative therefore *ours*. To understand the autistic community I immersed myself in their organisations and their lives, recognising my place on the spectrum, albeit that my life may be affected less than many of those I worked with. My reason for this was to get to know and be known by the autistic community and to understand their concerns from their point of view. I started this process by presenting my initial research in an informal session at Autscape in 2007. This led over time to the development of friendships and research relationships, leading to some of the participants in this study taking the role of co-researchers. Their interest and commitment was such that some were not only involved in the go-alongs and subsequent member checking, but also read and provided feedback on the writing and organisation of the thesis. Others who did not take part in the go-alongs suggested areas I might like to investigate further and provided technical information. Attending autistic led conferences has meant sharing accommodation and on other occasions, I have stayed in participants' homes as part of data collection. This I suggest to a large degree has confounded Oliver's statement that 'researchers never reveal as much about themselves as they expect

to be revealed' (Oliver, 1992:111). How much people know me varies as in any other aspect of life. Some participants do not know much about me, or know a lot about one aspect of my life and not others. While others know a great deal, about what is relevant to them, others are not interested in even basic facts my presence is enough. Some may find too much detail overloading, while others know more about my weaknesses than is comfortable and significantly more than old friends.

At first, this concerned me, as previously as a social worker I always maintained a professional distance, especially with those perceived as 'vulnerable'. However, the close working collaboration I formed with several participants produced highly significant data, as we will see in the case studies. Barkaoui et al's study investigating changing cognition in older people, found that similar fruitful, mutual, long-term friendships developed (Barkaoui et al., 2011:64). They argue close relationships between participants and researchers enable them to focus on the 'microgenetic' details of the participants' functioning (Barkaoui et al., 2011:63). Oakley makes a similar observation in her research with pregnant women, suggesting that research 'about people' is only successful if the researcher invested in the relationship (Oakley, 1993:229).

I found that the degree of equality between the participants and me was determined by the intensity of our interaction. The more intense interaction the more we broke through the researcher/participant hierarchy. For those such as KM, IJ and MN our interaction was very intense involving the negotiation of what Fine terms the 'hyphen' (Fine, 1998; Jones and Jenkins, 2008).

Othering

Before discussing the hyphen, I will look at Fine's discussion of researchers' tendency to 'Other'. She suggests, as I do, that often when researchers write about those they perceive as marginalised, they speak for and about them, robbing them of their 'whole complex humanity'. She argues this can often decontextualize their experience, the researcher speaking for rather than with them, creating them as 'Other' (Fine, 1998:139). This resonated with me as I wanted to avoid , as I said previously, 'business as usual ableism' (Kumari Campbell, 2008:152). I also wanted to avoid the usual dichotomies of the 'brave autistic person' 'overcoming their disability', exoticising e.g. focusing on savantism, or autistics as passive victims of their disability. Instead, I wanted to get alongside autistics, sharing commonalities and differences. This is in itself, as Fine argues problematic, with the potential to lead to the homogenisation of experience through arguing for commonalities, thereby ignoring difference and at the other extreme separating autistic experience from our common humanity. The latter Fine describes as 'othering', separating people as for instance 'unworthy dangerous, immoral, pitiable, victimised, and damaged'. I have witnessed this occurring over many years as a social and support worker, those who are different being 'othered' to excuse the behaviours of those 'in control' that undermine disabled people. These range from rendering the person invisible, undermining them, indifference, and the arbitrary imposition of others' cultural expectations, to culturally sanctioned abuse to gain conformity. Fine argues the way to avoid 'othering' is to '… construct texts, collaboratively, self-consciously examining our relationships with/for/despite...' those constructed as Other, to resist doing this ourselves (Fine, 1998:139).

The hyphen

Fine argues that exploring the 'hyphen', that is the gap between the participants' and the researcher's experience is a way to avoid 'othering'. The hyphen prevents researchers glossing over rather than learning about the experiences of those who are different. Fine argues the hyphen is the space that straddles the difference between each person's experiences. She argues this difference is often ignored protecting the privilege of the researcher, keeping the participants at a distance (Fine, 1998:131,139). My application of the hyphen to this study is shown in figure 14 below:

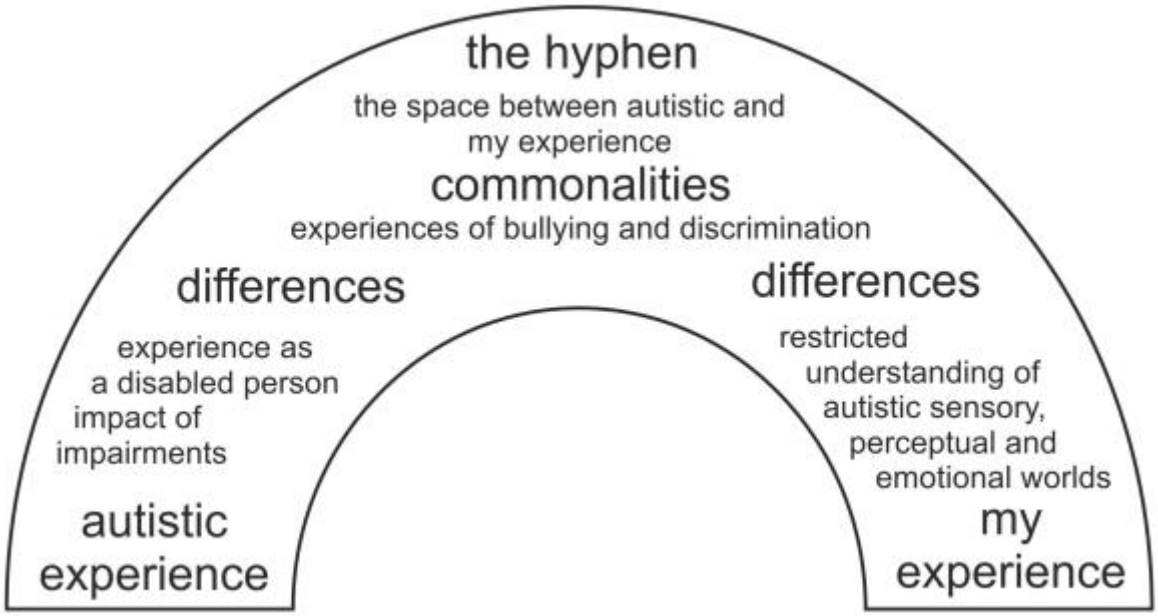

Figure 14. My application of the hyphen to this study (after Fine, 1998)

Jones and Jenkins suggest that exploration of the hyphen creates a complex, uneasy, unsettled relationship, based on learning (about difference) from the 'Other', rather than learning about the Other (2008:473,471). This has been key in informing

the on-going, sometimes terse, dialogue with the participants throughout the gathering and analysis of the data in this study (Fine, 1998:139,140).

I use the hyphen on several levels, first to explore the differences between the participants' and my perception of space. This helped to prevent missing crucial data and distorting analysis by my over identifying with the participants. Secondly, concept of the hyphen was fully employed during member checking as we explored the participants' functioning and what made it problematic or not in the different spaces we encountered during the go-alongs. Thirdly, with some of the participants we entered a different level of looking at how each other's presence in space affected the other. This was to examine the effect of typically developing people's behaviour on autistic demeanour and vice versa. The hyphen was most intensively engaged where there were strains in the research relationship, at first my reaction was to blame the participant. There was a temptation on a couple of occasions to think those involved were too difficult to work with. However, as I will illustrate in some cases they felt assault on their senses and I felt the same in relation to my emotions. Using my instinctual, emotional response, I felt a sense of injustice and a need to try and put things right. I guessed the participants involved might also have felt a sense of injustice, more acute because they commonly face being misunderstood with no redress or resolution, compounding their sense of isolation. Instead of walking away without knowing why things went wrong and not knowing how to put them right, we set about unpicking what had occurred, providing crucial insights into the sometimes conflictual relationships between autistics and those they share space with.

This was crucial in identifying the effect of largely unwritten and preconscious socio-spatial norms and expectations on the spatial comfort of autistics and those sharing space with them. A considerable number of observations or occurrences seemed not to be that important and the temptation was to ignore or dismiss them. However, by keeping the hyphen in mind and trusting my emotional reaction to events, through our close relationship, I was able to explore them with the participants. Staying with my negative initial judgements, not employing the hyphen, or having an emotional connection to the participants would have, as I will show in the case studies frozen the data. This could have meant I remained stuck with the view of their demeanour as deviant rather than merely different, leading to a thesis with a very different flavour. This could have aligned findings of this study to medical and other negative autism discourses; however, the application of the hyphen opened up the reality of the participants' daily experience of space.

Participant Observation

Accompanying the participants during their daily activities led to my role being primarily that of participant observer. This meant juggling visibility, invisibility, vulnerability, taking what seemed sometimes to be emotional risks and being alongside the participants or not as the occasion demanded. For instance if I was going to someone's workplace, I tried to be invisible or if we were going on a journey or a day out I would try to blend in as a friend. I would try not to take the initiative sometimes when it was instinctive for me to do so, for instance finding a table in a restaurant. At the same time, I had to try to take everything in and retain it, not knowing what might be useful and what not. Writing everything down as soon as possible whether I thought it was important or not, using the technique of process

recording[12] learned when I was a social worker. Sometimes I would be concerned that some of my observations may feel intrusive or offend the participants for reasons sometimes I could not articulate, and then find the person responded in a very matter of fact way. Sometimes I felt the studies contained too many of my observations. However, the difference between my observations in this study and other studies is that they were always discussed with the participants, who had the final say regarding what was included or not in the final thesis. Several also read and commented on the thesis as I was writing it up. Through these lengthy discussions, we often discovered issues neither of us had considered before or the participant had to unpack them so I could understand. The focus was on working alongside, with and from as 'us' not 'Other' (Jones and Jenkins, 2008:480). In this study, as Tutu says when describing Ubuntu, 'we are all part of one another bound up in the great bundle of life' (Tutu, 1999:35).

Research methods used

Methods – unstructured go-along interviews

My first consideration in choosing my methods was to make them as accessible as possible. Therefore, recognising the differing requirements of autistics, I offered a range of ways people could participate, the main ones being online and real-time focus groups. For those who do not like group interaction I created a blog, where people could leave accounts of their experience. I also offered individual, live and telephone interviews and go-alongs for those who wanted to participate on a one-to-one basis. This meant from the moment of joining the research the participants

[12] Process recording involves writing a document in which you recollect and process your entire session with a client including your emotional responses and evaluation of the encounter.

determined what form their involvement took and in doing so determined the data collection method used for this study. This meant the primary method of data collection changed from focus groups to go-along interviews. Many of the participants having a more concrete idea of what this would entail than a focus group, readily offered to let me accompany them during their daily activities.

Appropriateness of the go-along method for working with disabled people

Carpiano argues go-along interviews have more credibility with participants than other styles of research interview, termed 'drive-by research' by his respondents, due to their experience of researchers collecting their data and leaving without sharing their results (Carpiano, 2009:14). Other disability researchers have described this as 'academic tourism' (Barnes and Mercer, 1997). Carpiano also found his respondents were dissatisfied with the focus on health behaviours in a similar way to many autistic people who resent the focus on impairments rather than their strengths. In his research and in mine the participants appreciated go-alongs because they indicated the researcher's wish to gain first-hand experience of their community. Another criticism is that researchers gain more from the research in terms of job and profile whereas the participants do not. This criticism does not consider the time and financial demands of on-going research, income from academic publications is nil and from books is minimal. I will continue to research through the development of a virtual online or live centre with autistics and other researchers to continue to research. Like Granek, who describes being changed by the communities she works with, I have changed, becoming intertwined and connected with the autistic community in ways that move beyond considerations of career advancement (Granek, 2011:2).

Go-alongs – background

I first discovered go-alongs through the work of Kreutz, who examined aboriginal children's experience of place (Kreutz, 2009). This led me to Carpiano's review of go- alongs used in his research into the implications of place for health and well-being, and Kusenbach's use of go-alongs in her study of how problems in five urban neighbourhoods affected the activities of their inhabitants (Carpiano, 2009; Kusenbach, 2003). Hart similarly accompanied children in their locality, observing and talking to them about how they used their environment (Hart, 1979:67). Recently they have been used been used by Lund to understand mountaineers embodied experience when climbing and by Stiansen in her work with older women (Lund 2006 quoted in Pink, 2007:246; Stiansen, 2011). Others who have used similar methods include Wunderlich who talks of discursive walking as an unconscious act, which allows interaction with and reflection of the environment (Wunderlich, 2008:125ff).

Go-along interviews

Go-alongs are a qualitative, ethnographic research method, where the researcher accompanies the participants as they go about their daily lives, talking as they 'walk'. (Lund 2006 quoted in Pink, 2007:246). During the go-along, the participant and I would discuss a wide range of issues; apart from two participants, they needed no prompting, steering or encouraging to talk. The two participants who needed prompting had issues with knowing when and how to join in or initiate conversations, which I discuss in the case studies. Another person had more difficulty discussing spatial use when member checking, because they were without contextual, spatial prompts to guide their discussion, the implications of which I will discuss below. The main benefit of go-alongs is that they are user-led, the participant choosing where, when and how long the interview is. This allowed the participants to integrate the

research into their daily schedule, and to choose what aspects of their spatial perception and functioning they wanted to show me. Go-alongs are very flexible, the participant can extend or reduce the session as they wish or change where we go at short notice. Often we negotiated as we went along depending on how each was feeling. The participants took the lead and I was learning from their expertise.

The advantages of go alongs over traditional interviewing

Go alongs in comparison to traditional interviewing, mean the participants do not have to remember a certain day, time and place that is outside their schedule. They also do not have to incur additional monetary or time costs, as in most cases they would have been doing the activity anyway (Carpiano, 2009:267ff). For many autistics' issues/differences in executive functioning sometimes mean they are late, come on the wrong day or miss a meeting, incurring extra financial and time costs and embarrassment. Another advantage of go-alongs is that the participants could judge in advance how the environment was likely to affect them, weighing up whether they wished to risk a melt or shutdown or how they could strategize to prevent one.

The major advantage of the use of go-alongs with autistics is that they take place in the context of daily life, providing numerous spatial and social cues for discussion (Kusenbach, 2003:259). These cues would be absent in a traditional cognitive interview or when filling in a questionnaire (Maras and Bowler, 2011:1). This is important for autistics with impaired episodic memory and autonoetic awareness, which means they often cannot remember their involvement in or visualise past events (Boucher, 2007:261; Faran and Ben Shalom, 2008:87ff; Toichi, 2008:156). Episodic memory and autonoetic awareness combine to allow recollection of

experiences through mentally reliving what was experienced at the time of the original event (Tulving, 1983; 1985 quoted in Gardiner, 2008:8). Bowler et al found that remembering in autism is less ‘remember-like’ in terms of subjective detail and more know-like or factual relying on 'knowing' through semantic memory at Ben Shalom’s level 3 (Ben Shalom, 2009:3f; Bowler et al., 2000:301). Gardner argues that for instance ‘One can know of many previous visits to Paris without re-experiencing anything that happened during any such visit’ (Gardiner, 2008:9).

Therefore, in a traditional interview, those with impaired episodic memory may be able to tell the interviewer they had visited a place many times, but not what happened during the visit. For instance, JS in Boucher’s study would use semantic memory to remind himself of conversations or the facts of a visit, such as arrived on ‘Friday…; took a taxi to the hotel; met X… went to bed' (Boucher, 2007:256). The factual recounting of events is of limited use when attempting to autistics’ experience of space. Go alongs overcome this by allowing the person to recount their experience in real-time with its associated contextual cues (Boucher, 2007:261). Illustrating the importance of this, JS says his memory is ‘state dependent’ i.e. he cannot remember technical terms unless he is in a work related situation or has his laptop in front of him (Boucher, 2007:256). Traditional interviewing may also be frustrating for participants with short-term memory and motor planning issues, which may affect their ability to speak and organise their dialogue. However, the use of go-alongs combined with email and Facebook chat, means they can more fluently express themselves, and respond to requests for clarification.

Disadvantages

Interviews in whatever form are as Kusenbach argues contrived to some extent, but I think this is significantly overcome by the arguments I have outlined above (Kusenbach, 2003:464; Scott et al., 2009:404).

A significant issue in some cases was that sometimes people tended to try and focus on me instead of the person I was with, especially when the person did not initiate conversation or become curious about my role. Another disadvantage is that go-along's and the resulting member checking is hugely time consuming. However, I am firmly of the opinion that this is far outweighed by the high quality of the data, which allows a detailed understanding of the spatial experience of the participants in this study.

Application of the method

Therefore, the contextual nature of go alongs addresses many of the issues in using traditional cognitive interviewing with autistics. They were structured not only by the participants, but by the spaces and events we encountered. I listened rather than asked questions, except when seeking clarification, which was usually during member checking rather than the go-along. One of my concerns was that the experience of the go-along would become my experience rather than the participants'. Some cases particularly in chapter 3, where initial discussions focused more on sensory issues, relied a lot on my unexpected observation of social differences. However, during member checking the participants involved said the comprehension of social norms was difficult, which may have been why they discussed them less. I could have questioned the participants more about this, but I did not want to ask leading or intrusive questions. This was a major concern, leading

or wrong questions, or on some occasions any input whether verbal or gestural would have distracted the participant from their concerns and line of thought. For some this was already compromised by the spatial, social, and sensory distractions of the go-alongs.

However, member checking counterbalanced this as the participants could correct any misinterpretations. This appeared to work apart from one person who seemed not to fully understand the focus of this research. Their intense schedule meant I did not get the opportunity to explain it in a way they could retain. Therefore, I withdrew their data, as I was not clear I had their informed consent.

Member checking

After each go-along, I would up write its events including my thoughts and feelings, which I then shared with the participants. This formed the basis for discussion, reflection, and analysis of our experience. Sometimes during this initial write up, I would contact the participants for clarification, this often opened up areas that neither of us had previously considered. The participants read or in the case of one person who had dyslexia, had read to them drafts, including the final draft. During this process, I triangulated our experiences with autistic authored writing and existing research, also sharing this with the participants. On-going triangulation allowed me to identify similar experiences, keywords, and themes to contextualise my findings.

This led to the merging of four strands of experience, the participants', autistic literary and online accounts, academic discourse and my own, each informing the other during on-going discussions and analysis of the data with the participants, illustrated in figure 15 below:

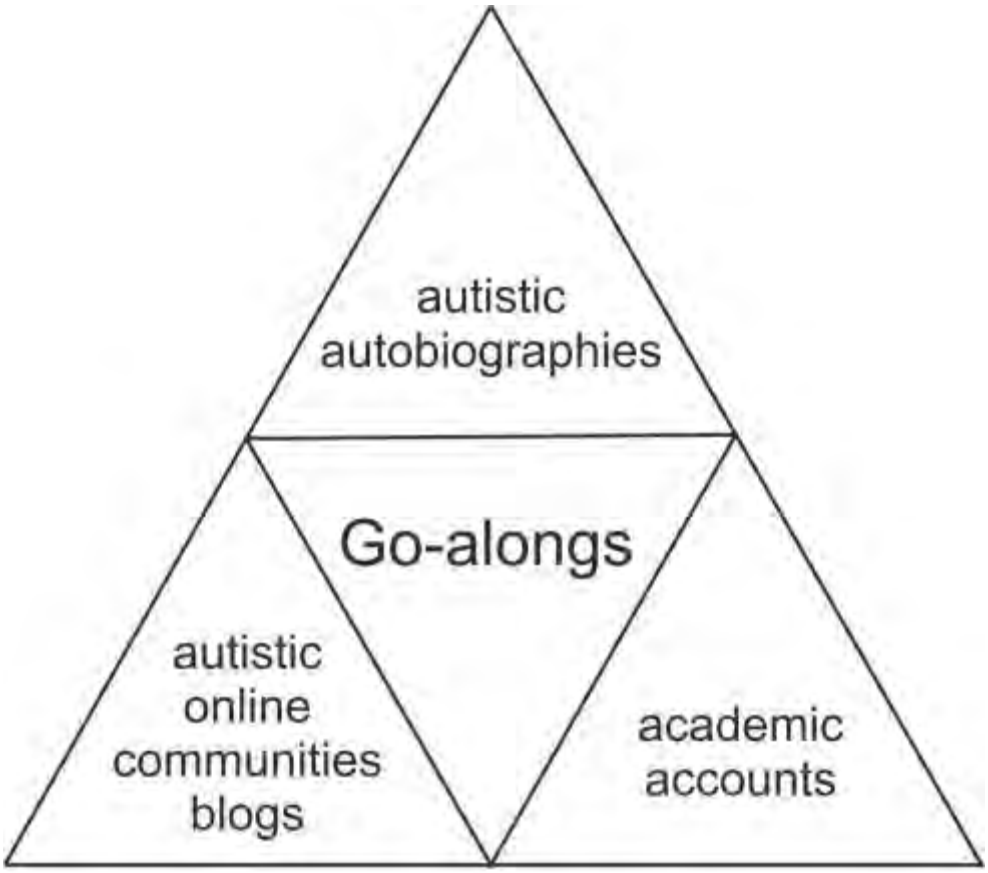

Figure 15: Triangulation of data

This reiterative process aligns with my argument that space is an in process spatial and social entity rather than fixed and abstract. It also corresponds with the arguments of Seamon, Cresswell, Thrift, and de Certeau. They argue space, in this instance research space, is constituted through reiterative social practice, being made and remade daily in a similar way to my/our analytical process, as new avenues for exploration and understandings came to mind (Cresswell, 2004:39; de Certeau, 1988:117; Seamon and Sowers, 2009: no page numbers; Thrift, 2008). A crucial part of member checking was continually being aware of and negotiating the hyphen to attempt to avoid either myself or the participants slipping into assumptions through not fully exploring our different perceptions. The hyphen was also important

in negotiating our way through misunderstandings, especially those affecting our spatial comfort.

When I shared the initial drafts of the go-alongs with the participants, I would always try to meet them face-to-face so I could address any differences in perception or concerns there and then, checking they still agreed to their data being used. This was because I did not want the participants to read something that might be unsettling without being there to support them and make changes.

Member checking was a crucial element of this study, leading to lengthy discussions of issues raised by the data, revealing issues overlooked by other studies. For instance, why KM kept bumping into people; I assumed it was solely due to her motor planning. When I asked KM about this, with some trepidation, as it can be disturbing to have your clumsiness brought to your attention, she replied in a very matter-of-fact way that it was due to ‘motor action’. This opened up another crucial topic, providing key search words to trawl the Internet to inform our discussions.

Analysis of the data –thick description and saturation

As the study progressed, I realised the data and our discussions covered a wide range of topics, many of which had not occurred to me before, for instance, the role of the participants and my emotional state on each other, and the home as a public space. The huge quantities of data from the go alongs and the intense dialogue arising from them meant that data gathering quickly reached saturation point and risked becoming unwieldy. I realised that recruiting further participants could compromise the quality of the research process, such as the flexibility and accessibility of data gathering and analysis. As Bowen argues there is no clear cut-

off point for deciding when saturation occurs, like him, I wanted to remain faithful to the participants' accounts (Bowen, 2008:149).

The high density of the data and dialogue created an iterative process, where it was sometimes not possible to create a linear discussion or progression of the findings and the ideas arising from them. Instead, a many-stranded account emerged, various strands running alongside each other like an electricity cable. This made disassembling the data into who said what, and triangulating with autistic authored literature and academic discussions complex.

Validity - Methods

As you can see from the discussion above, member checking was an important part of ensuring the rigour and validity of this study. From the start of this study, I resisted any suggestion of using recording equipment, as I felt this would interfere with the participants and my spatial experience. In addition, the transcription of tapes and videos even using computer applications would absorb huge amounts of time that I felt would be better used listening to and interacting socially and spatially with autistic people. Also from my experience with computer graphics packages, the focus when using applications such as NVivo can move to exploring its functionality and worse can bring the focus to what the researcher wants to know rather than what the participant wants to tell them.

Validity - positionality

Another aspect of validity is making the positionality of the researcher clear, as I have done, through the introduction and analytical framework of this study. Hammersley highlights the importance of this, arguing that ethnographic research runs the risk of becoming an ideological device if the positionality of the researcher is

not made explicit and the subsequent description presented as the only one possible (Hammersley, 1990:609).

Validity versus authenticity

There is considerable debate regarding the validity of qualitative research and many arguments in favour of quantitative research, which is seen as more 'scientific'. However, Thomas argues this is a ‘folk view’ of science as a linear process rather than the reality which is the use of many different methods by the various scientific disciplines in a 'fluid and multifarious' process similar to that of qualitative research (Thomas, 2012: 28). What is important Thomas suggests is the link between the methods used and the question. In this study, very careful consideration is given to the methods used to answer my question. This was begun while setting out my positionality, building my analytical framework for autism and space. This suggests that both autism and space can only be understood within the continuum of life experience, through 'accumulation' of 'understandings' rather than concrete facts (Thomas, 2012: 28, 30). As such I agree with Clark et al's conclusions based on the arguments of Seale and Silverman (1997) Lincoln and Guba, (1985) and Gobo, (2008), that we should focus on credibility, authenticity, trustworthiness and fidelity of the data's interpretation which has been the focus throughout this study (Clark et al., 2012:38f).

Validity of first person accounts

Those who favour quantitative methods might challenge the validity of self-reporting, the accounts relying on the introspection, of both participants and researcher. I suggest this is an important part of understanding another’s world. However, our accounts are subjective and transitory therefore, how do I know they are valid? I go

back to the arguments I presented above, the ‘truths’ of this study are shaped by my positionality and analytical framework, therefore in many ways they are unique to this study. Another person may approach this topic in a completely different way. As such the study is inevitably biased by my positionality and ways of working with the autistic community. I can only say that the findings of this study are contingent and contextual and therefore its 'truths' temporary due to the transitory nature of human subjectivity and spatial experience. Hoffman argues that there is no single truth or accurate account to be found, but rather shared truths derived from collaboration with the participant (Hoffmann, 2007:319). Dennett quoted in Jack and Roepstorff, argues that scientists should only go so far as making claims about the beliefs that subjects have about their experiences. They say researchers should stop short or ‘reserve judgment’ about them being true (Jack and Roepstorff, 2003:xi). Which brings us to the question of whose truths? This study is about the participants’ truths, from their perspective, in the context of their daily life.

How I chose which participants to focus on

I met the participants through user-led organisations of autistic and neurodiverse people such as Autscape, LondonARM, and DANDA. My criteria for inclusion were that the participants wanted to participate and would help me answer my research question. In reality, people were self-selecting, joining because of their negative spatial experiences or from curiosity about the study. I discussed spatial issues with many autistic people having significant if sometimes brief contact with 20 people and on-going contact with those whose cases are presented here. I would have liked to do more work with everyone who contacted me, but that was not possible, sometimes due to the personal circumstances of the participants and in large degree to the parameters of doctoral research. However, following the completion of this

thesis I will apply for further funding to continue this research. I concentrated on participants whose data illustrated issues either not discussed or only superficially mentioned in autism related literature and those where the participant's spatial demeanour challenged me emotionally in a way I felt it was important for others to understand.

Organisation of the data and analysis

The participants in chapter 3 apart from Debra were diagnosed autistic in childhood whilst, Debra, KM, IJ, and MN were diagnosed as adults. The data is organised according to Ben Shalom's typology of autism and my division of her Type II into those with less severe and those with severe issues with executive functioning as illustrated in table 5:

Ben Shalom's typology	**Type I**	**Type II**	**Less severe executive function - less overt and extreme consequences for their spatial functioning**	**Severe issues with executive function - resulting in homelessness and alienation from their community**
CD		●	●	
EF		●	●	
Debra		●	●	
OP		●	●	
AB		●	●	
KM	●			
IJ		●		●
AB		●		●

Table 5. Organisation of the data according to Ben Shalom's typology and my interpretation of it (Ben Shalom, 2010).

The data from the case studies is then subdivided into chapters as illustrated in table 6 below:

Chapter	**Participants**	
Chapter 3	CD	Female undergraduate in her early twenties
	EF	Male graduate, late twenties
	Debra	Mid forties, project manager
	OP	Early fifties, expert in electronics and musician
	AB	Early thirties, professional musician
Chapter 4	KM	Mid forties, multi-talented, well on her way to the top of her profession
Chapter 5	IJ	Mid fifties, parent, activist, trainer
	MN	Late forties, parent

Table 6. organisation of participants into chapters and brief biographies

Chapter 3 presents the data of those I perceived as having less severe issues with executive functioning, experiencing less overt and extreme consequences from their social and spatial interaction, than those in Chapter 5. Chapter 4 presents data from KM, who appears to fit Ben Shalom's Type I, having severe sensory integration issues affecting all five senses plus motor planning, and proxemics. KM also experiences issues in all four of Ben Shalom's domains, motor, emotion, memory, and sensation/perception. Chapter 5 contains data from IJ and MN who appear to fit into Ben Shalom's Type II and who appear to have extreme issues with executive function, IJ who feels alienated from her home and community, and MN and her

family who have repeatedly experienced homelessness (Ben Shalom, 2010; Ben Shalom and Clemerson, 2011).

Chapter 4, looking at KM and Chapter 5 looking at the experiences of IJ and MN are extensive because the researcher/participant relationship involved extensive negotiation of the hyphen resulting in large amounts of data. This was because their demeanour challenged my culturally ingrained assumptions of what is socially acceptable. I had a nagging feeling that my assumptions were incorrect and unfair, not knowing why as I pursued the 'truth' of the situation with no 'map', until several months after my journey with KM, to guide me as to what I needed to understand and how. If I had gone along with my social assumptions, the data would have been limited and hugely distorted. By moving beyond them, I radically challenged many of my social assumptions, fundamentally changing the way I view not only autistic people's demeanour but that of others around me. This occurred through negotiation of the hyphen as we explored in depth the effect that sharing space had on each other's demeanour and our relationship. This allowed misconceptions, which could have remained hidden to come to the surface and set the stage for a deeper analysis of the spatial issues presented in this study. The understandings drawn from the case studies are then presented in my conclusion in Chapter 6.

Chapter 3: Short Case studies: those who have less severe issues with executive function

The cases in this chapter are located within the overall case study framework as key to understanding the spatial experience of participants who appear to fit Ben Shalom's Type II (Ben Shalom, 2010). Having fewer sensory issues, which apart from Debra's[13], appear to have less impact on their spatial functioning. EF has issues with noise and light which could be comparable to Debra's, but which are less apparent, his demeanour giving little indication of his emotional or physiological response. A reminder for the reader of their biographical details and type is outlined in table 7 below:

CD	Female undergraduate in her early twenties	Type II Fewer sensory issues and more social issues Less severe issues with executive function, with less severe consequences
EF	Male graduate, late twenties	
Debra	Mid forties, project manager	
OP	Early fifties, expert in electronics and musician	
AB	Early thirties, professional musician	

Table 7. Biographical details and categorisation by type

[13] Debra is an author and well-known mother of Bearsac and chose not to be anonymous. (Schiman n.d.)

Rather than present each case as a discrete entity, where the participants share commonalities I overlap them both in the narrative and their analysis to avoid repetition and hopefully to avoid objectification. Some of the data came from my observations, its relevance being confirmed by the participants during member checking. These discussions were less intense than those presented in chapter 4 and 5, possibly because spatial functioning has less immediate consequences.

The group appeared to have less dramatic issues than those presented by KM, IJ and MN, initially disguising the 'corrosive drip' of multiple, subtle daily misunderstandings and exclusions faced by them. Their less disruptive demeanour could signal to some that they have fewer spatial issues. However, the concerns highlighted in this chapter relate to the social and interactional spaces of daily encounters. These often difficult to articulate, subtle, nuanced, social-spatial expectations require preconscious processing and the consequences of not meeting them are may not be readily apparent.

However, when they are not met, those sharing space with autistics may have difficulty understanding what they are saying, despite the autistic person’s speech appearing to be ‘typical’, or the person may seem a bit 'off'. Such concerns may look trivial, but when not brought to awareness they hugely affect the assumptions made during interaction with autistic people and others who do not fit our preconscious spatial expectations. For instance, we instinctively expect others to respond and in some ways mirror our demeanour to enhance spatial harmony, not to do so creates varying degrees of spatial discomfort. However, this discrimination is a largely preconscious process (Giddens, 1984:4; Sapir, 1927b:137).

CD: a case of not being who you appear to be

The first case illustrates how these nuanced aspects of social space play out in real time. CD is a fashionably dressed, undergraduate, design student, in her early twenties, appearing no different from the rest of her peers. This participant was self-selecting, having an interest in design accessibility.

During an encounter she was showing me around the city where she lived. CD was studying the map to find an unfamiliar part of the city. A young woman of similar age and dress to her asked us where we were going. Not being good at taking verbal directions I stood to one side not taking much interest in the exchange. However, after a couple of minutes I could sense that CD puzzled the young woman. On her part, CD appeared not to be following what young woman was saying. The young woman looked puzzled, looked CD up-and-down and then drifted away. I returned my full attention to CD and she confirmed she had not understood the directions. An apparently simple encounter, but I was really struck by how the young woman looked at CD as though she was trying to quantify who she was, looked puzzled and then walked off without a final salutation. For reasons I could not fathom at the time, the incident left me with a great sense of loss, for several minutes the day that had seemed so full of possibility seemed dark. The effect of this led me to ponder the incident for several weeks, as I tried to understand the significance of what I had seen and its effect on me.

Apart from the emotional effect of this encounter, another reason is that CD's appearance is unremarkable, similar to that of many autistics, providing an example of the effects, although in this case subtle, of having an invisible disability. On the surface CD's demeanour does not appear different from others of her peer group.

However, the young woman giving CD directions quickly sensed that she was different but could not work out why. So what was happening? At first, I was puzzled, CD in my opinion, had little or no speech or behaviour differences apart from a quiet voice, with little intonation. This meant at first I could not work out why the young woman had walked off. Originally I assumed it was because CD did not fit in with the young woman's social expectations of her. This was at least partially the reason for my emotional reaction, reminding me of the sense of abandonment I have felt when I have been out of step with those around me, for no reason I could quantify. As I unpacked the incident, I concluded that CD's appearance did not match the outlook and demeanour the young women expected from her appearance. I found a possible explanation for this when I remarked to CD that I liked what she was wearing. She said her mother chooses what clothes she buys, but not when she wears them, as CD was quick to point out. Despite being a design student, CD says she is not that interested in clothes and there is so much choice she does not know what to buy. This may have caused a disonnance between her appearance and demeanour, including the absence of other subtle behaviours that would match the expectations infered by her appearance. These were also invisible to me as I am not part of their twenty something peer group, but were expected by the young woman giving directions.

EF: a case of making yourself invisible

EF's spatial issues meant he wanted to support this study. His appearance is unremarkable, similar to that of many other male graduates. EF is very sensitive to noise and light, he has motor issues, so moves carefully, deliberately, and slowly. However, unlike KM, who we will meet in the next chapter, he does not report motor planning issues or disunified vision. He is very quiet and unassuming, to the extent

of almost being invisible. EF appears to go to great lengths to avoid interaction, appearing to avoid communicating by nodding or shaking his head. He does this because he says it is difficult for him to speak and be understood.

I will discuss EF's speech further when I describe the afternoon we spent at the centre where he volunteers. First, I present the following episode, which illustrates how difficult interactional space is for EF, due to the mismatch between his demeanour and appearance, exacerbated by his difficulty speaking.

EF: attempting to meet the immediate demands of interactional space

EF asked me go with him to a comedy club he attends regularly. Perhaps a strange choice for someone who is noise sensitive, EF said that once the show started the club was quiet apart from laughter, so it was not too bad. As we left the club, EF came out of the toilet with a metre of toilet paper attached to his foot, which he was oblivious to. Another member of the audience, who was drawn into several of the comedians' jokes, so I knew he was a solicitor and of similar age to EF, pointed out the toilet paper. EF and the man faced each other and I could see, them having a conversation, which I could not hear. I saw that EF could not get his words, speech, and body language together to respond to the other person. The solicitor pointed to the toilet paper, but EF did not respond, the solicitor smiled, pointed, and explained again. The solicitor then looked confused and slightly embarrassed as if he had made some kind of 'faux pas', EF still attempting to speak, but otherwise presenting relatively blank facial and body language. When I discussed this with a male friend, he said the solicitor could have thought that EF was ridiculing him or EF thought that the solicitor was ridiculing him. As in the previous example the solicitor walked off without a final salutation. EF turned on his heel and headed straight for me to tell me

that he had arranged a lift, so I would have to go home on my own. EF said that having to tell me about his lift home meant he was focusing on this and could not respond to the solicitor, noticing the toilet paper on his foot.

Analysis – general spatial issues

First I discuss how these incidents relate to space, then I analyse the concerns common to both CD and EF. This is followed by showing how EF's verbal articulation, compounded the disonance between his appearance and his demeanour. The accounts outlined above could seem insignificant, when reduced to concerns regarding social interaction and communication. However, as I set out in my analytical framework, space in the context of this thesis is not an abstract concept or at the other extreme a purely visible one. Each space being determined, as I outlined in my typology, by its ideological and contextual elements that are culturally determined.These shape the expectations of the social and interactional spaces of the encounters above. The dynamics and consequences of not meeting these spatial-social expectations is the focus of this chapter.

I began by thinking about the issues raised by the two incidents from the standpoint of CD who says she often feels excluded, and EF’s who has difficulty getting others to understand his speech and joining in conversation, compounded by sensitivity to light and noise. CD and EF’s concerns are not apparent from their appearance. Their experience led me to develop a framework for space to account for autistics’ and those around them’s social discomfort within what I came to term interactional space. I moved from thinking of the effects of space on autistics as mainly sensory and physical, to consider the social space of the street and the club, then the interactional space of face-to-face encounter. In this case social space is determined

by the ideologies of British society and the context of the inner city. Added to this are the ‘twenty/thirty something’ cultural norms that inform their demeanour within interactional space. Not being part of this age group I too may have missed many of the social and spatial cues that autistics also overlook.

CD and EF: analysis of the case studies

CD and EF: the effect on space by being present

Superficially CD and EF’s demeanour fits the cultural norms of social space, as they are quiet and unassuming. Therefore when I was with them they received little comment. But when they began to speak differences would appear. However, even without making demands on the space, its dynamics are still altered. At its most basic level this may be the difference between an empty room or street and one with others in it. Whilst occupying the space the demeanour of each person affects the comfort of others in the space. Even if they are inactive, 'normality' often demands certain types of social interaction, governed by the ideology of the culture of the majority of users of that space, despite the person being inactive.

For instance walking down a street rather than standing still. Some autistic people, including CD might stand still due to indecision, but this could be construed as loitering and so on. Whilst their appearance and demeanour remains within the social expectations of that space, their presence is benign. However, if they began to argue or someone who fits the stereotype of a socially demonised group enters the space, then tension ensues. In this instance CD was not affecting the contextual or ideological aspects of space, except by presenting as a woman of fairly conventional appearance and demeanour, providing reassurance rather than a threat.

CD and EF: a case of not meeting social expectations of appearance; halting communication, and the intricacies of spatial interaction

In the two examples it was not the ideological or contextual elements of space that were challenged. Instead the confusion CD and EF's demeanour caused the solicitor and the young woman was within interactional space. Although it could be argued the contextual element of the street and more so the club, was problematic as those encountering CD and EF, due to institutionalised disablism were not expecting to meet a disabled person, and if they did they would expect the person to 'look disabled'.

Although I was outside the interactions my emotional response to both situations was one of sadness and frustration. When we discussed, the incident with the map, CD said that comprehending and complying with social norms was one of the most difficult aspects of her spatial experience. As I have already mentioned as I watched the woman leave CD, I went from happiness to sadness at facing the subtle, harsh realities of being autistic and my own life at certain points, beginning to have some sympathy towards those who justify wanting to cure autism. This instance illustrates the layers of perception that create different spaces, within social space. Everyone around us was going about their business, while the young woman who tried to show CD the way was left puzzled, I was sad and CD was left with a feeling of déjà vu. This illustrates the effect of encounters in interactional space, which ripple out to affect the personal space of observers, and their social or interactional space, in this case, the club or the street.

Trusting my emotional response led me to want to know what was happening in the social space of these encounters that led to the solicitor and woman attempting to give directions to walk off. Why did these apparently innocuous incidents leave me

feeling so unsettled, but not knowing why, indicating to me on a gut level that they were important. Why was I having such a strong emotional reaction to occurrences not even commented on by the participants? My feeling was that these situations may occur quite regularly, raising no comment from the participants until brought to their attention.

CD and EF: a mismatch between demeanour and appearance

The significance of these incidents emerged as I analysed the data, examining in detail the dynamics of what occurred between the participants and those they met within interactional space. Initially it seemed there was a mismatch between CD and EF's appearance and their social demeanour, confusing the solicitor and young woman. CD and EF's appearance not matching their expectations of people of similar appearance to those they had met in the past (Goffman, 1990:13). This meant the solicitor and the young woman were not able to create what Goffman terms a 'socialised trance', with CD and EF (Goffman, 1957:47). Goffman describes this as consisting of an episode of 'talk' which places the participants in a spontaneous, mystical social space, with a life of its own, its own demands and boundaries. Those engaged in the space commit themselves to each other, despite the potential for the 'talk' to create its own heroes and villains depending on each individual's social competence (Goffman, 1957:47).

An example of this and its effect on social space is a recent encounter I had in a coffee shop. I was getting up having finished that day's proofreading when I noticed a young woman hovering, obviously looking for a seat. I said, 'you can sit here, I am going' and she said, 'there are not many free tables today'. Both of us then rounded up our mini conversation with smiles and thank yous, there was a definite

connection, each making the other feel comfortable and a defined end to the encounter. Both of us contributed to a comfortable, if brief interactional space, the elements of which, before I began this study I would have been hard pressed to articulate, following Sapir's notion of unseen and unwritten socio/spatial rules (Sapir, 1927b:137).

Goffman says that farewell rituals are important as they establish what the participants might expect on their next meeting (Goffman, 1972:41). In this case, my expectation is that the next time I go to the coffee shop someone will also offer me a table, the friendly ambiance of the coffee shop maintained by others mirroring my demeanour. When I witnessed CD and EF's encounters, with the young woman and the solicitor, I got no sense of this connection and the establishing of future conduct. It should be borne in mind that often in such encounters although we probably will never see the person again, we always end the encounter as if we will. This form of interaction is termed 'phatic communion' by Malinowski to describe the non-referential use of language, i.e. smalltalk, to share feelings and establish a mood of sociability, rather than to communicate information or ideas (Malinowski, 1989:315). Brown and Levinson argue that the structure of this type of interaction is an innate, primordial element of many social encounters (Brown and Levinson, 1987:44). This suggests to me that the interaction outlined above is an innate ritual many aspects of which are preconscious at Ben Shalom's level 2 and therefore difficult for autistics to follow and respond to (Ben Shalom, 2009:589f).

Smalltalk is not the only aspect to Goffman's 'socialised trance' expressed through a multitude of signals such as facial expression, body language, gestures, choice of words and tone of voice (Goffman, 1957:47f). These are important in interactional

space as they help individuals to orientate themselves to the persona of the individual they are talking to and their values. From this information those who are being spoken to start to adjust their demeanour to that of the instigator of the conversation to create a harmonious interactional space, as I did in the coffee shop (Goffman, 1957:47f).

CD and EF: dis-ease through not meeting the expectations of social space

However, CD and EF did not create this 'socialised trance' during their interaction with the young woman and the solicitor. This infringed the social and moral expectations of a casual encounter, to remedy this, Goffman suggests, one of the people in the encounter should mediate to compensate and restore the status quo. In this case both the young woman and the solicitor were left at a loss as to how to do this, hence their confusion (Goffman, 1957:47f; Goffman, 1971a:13). Most typically developing people can right social misunderstandings quickly, to do so reflects on their moral and social competance (Goffman, 1971b:13).

I would have indicated I understood even when I did not, employing body language and speech to say goodbye pleasantly before returning to my map, after the young woman had gone. However, CD and EF were not able to create the demeanours to allow this to happen, so the solicitor and young woman could pass on believing they had been helpful, saving their moral and social 'faces'. Many autistics argue this is lying and find the typically developing population's behaviour in this area maddening (Ford, 2010:2).

Brown and Levinson describe 'face' as consisting of a set of 'wants' that only can be satisfied by others' actions including their expression of wants. I suggest that maintaining face is an important determinate of the comfort of social and

interactional space for autistics and those they share space with as we shall see in later chapters. Brown and Levinson argue it is in the mutual interest of those engaging in interaction to maintain each other's face and that some acts are face threatening as we can see in these encounters (Brown and Levinson, 1987:60). They argue that 'face' is the public self-image that each person wants to present, having two aspects. The first is that of negative face, the right to create personal boundaries, privacy, freedom of action and freedom from imposition. The second is the positive face, a consistent self-image that is appreciated and approved of by those interacting with them (Brown and Levinson, 1987:61).

As it was the solicitor and the young woman's spatial experience was interrupted by a puzzling encounter where both may have felt somewhat 'put out'. They were trying to be helpful, to meet the ‘wants’ of CD and EF. But they seemed not to respond, or respond in the way the woman and the solicitor expected and for no apparent reason. EF's difficulty in speaking could have been assumed to be due to alcohol or drugs as we were in a club. In both instances they were one-off encounters and the other person could walk away. In a closed environment such as the workplace, these incidents could lead to tension among co-workers, the assumption being that the person was lacking interest or being deliberately unhelpful or aloof.

The incidents with CD and EF were amongst the most poignant in my data. The typically developing people genuinely wanted to be helpful, but were puzzled by the response they got from CD and EF. CD and EF for their part did their best to try and interact, but were left ‘in mid air’ because their demeanour did not fit. The global ascription of ‘impairments’ of social interaction and communication to autistic people, of which this is an example, gives little help in understanding the detail of the

intricacies of these differences in real-time. Developing an understanding of incidents such as those involving CD and EF became a major element of the analysis. How could I present what was going on in a way that would enable both autistic and typically developing people to understand these dynamics and how they affect each's spatial comfort.

As we have seen my initial response to what I was seeing was an emotional one, triggered by deep-seated cultural patterns which as Sapir suggests, are not so much known as in this case felt (Sapir, 1927b). I began to appreciate the significance of being engaged emotionally in the research, rather than the traditional solely 'objective' stance. Using emotion and instinct became an important aspect of analysis, but one which was always balanced against the participants' accounts. Without my emotional reaction, the significance of these two incidents would have been lost. The idea of 'knowing by feeling' is difficult to articulate as it is preconscious in Ben Shalom's terms, involving as Goffman describes the 'sensing of certain behaviours' (Ben Shalom, 2009:589f; Goffman, 1956:268). Despite the elusive nature of both, I strongly suggest they have a centeral role in understanding autistic people's spatial functioning and the wider population's understanding of it within social and interactional space (Ben Shalom and Clemerson, 2011). The dynamics of sensing and preconscious processing are elusive and difficut to articulate. But not to understand their significance and investigate their effect on spatial interaction, leads to, as was the case with CD and EF, an unsatisfactory experience of spatial encounters for autistic people and those they share space with. CD said this was one of the most difficult aspects of her spatial experience and EF said he thought the solicitor had just walked off because he could not understand what EF was saying.

However, I felt it was due to more than this, I sensed the solicitor had preconceived expectations of EF's response, which as he began to speak, the solicitor saw would not be met. This left him not knowing how to respond to EF's difficulty organising what he wanted to say and then speaking. For both EF and the solicitor there was no clear way to articulate and resolve what was going wrong. Most of the time the solicitor and the rest of the typically developing population seamlessly, mostly preconsciously, present the correct unspoken social cues that are congruent with their appearance, body language, facial expression and speech according to their spatial context. In these situations, Goffman argues, not presenting the cues correctly can result in being 'discredited' by the other person. This person in turn also feels discredited, feeling they caused the impasse even thought it was not their fault (Goffman, 1956:268). This is especially so if they were trying to be helpful as was the case with both the solicitor and the young woman (Goffman, 1956:268). As a support worker I have seen this lead to unwarranted, unconscious resentment, where the impasse is taken out on the autistic person, when it was not their fault, often severely affecting autistic people's spatial comfort. These ideas will be explored in more detail in later case studies.

EF: a case of difficulty in speaking

To return to EF, to the outsider he appears to have a speech impediment, causing blurred, hesitant speech, made more difficult because his mouth does not shape his words as he speaks. This is compounded by him speaking softly and hesitantly, often making it difficult to hear and follow what he is saying. EF also says he has problems with sounds such as 'ch' and 'j', which sometimes cause him to stutter or bring his speech to a jarring halt. Additionally he finds it difficult to project his voice.

EF: analysis of how differences in presentation affect social space

In describing EF's issues with speech I am attempting to un-pick what it is about differently sounding speech and the mannerisms that may go with it. These issues often impede two-way conversation, with a knock on effect within interactional space, such as being dismissed as we saw above. This is to the extent of EF avoiding speaking where possible and when he does try, causing puzzlement and confusion with who people do not know him.

First, I will discuss some elements that impede EF's and some other autistics' ability to speak. Stuttering is due to several causes, nervousness, not being able to process their thoughts fast enough, the effect of physiological discomfort, being tired or overstimulated or other intrusive bodily sensations (anneurysm et al., 2008). EF says he stutters when he is nervous, especially when talking to strangers. He says this is compounded by having to focus on motor planning to produce the sounds, in particular remembering to move his tongue.

To understand what made it difficult for EF to be understood I began to unpick what made it most difficult for me to understand him. One of the first things was that I could not get additional cues to what EF was saying from looking at his lips, as he does not use them to shape his words. Skipper et al, argue lip movement is important where there is difficulty in understanding speech, the motor processing areas of the brain of the hearer becoming engaged to literally 'hear' the person's lips and 'see' them speaking (Skipper et al., 2007:2397). This is what I do, as I find it difficult to hear when there is background noise, such as the noisy buses and streets EF and I encountered during the go-alongs.

Another skill connected with speech that compounds EF's reluctance to speak is not knowing when and how to join in conversations. Nazeer reports similar issues, saying he relies on others to draw him into the conversation (Nazeer, 2006:118). Smith, who is also autistic, also says that initiating conversation is a major issue, due to difficulties initiating the motor execution and planning required to make the sounds in addition to formulating what he wishes to say (Smith, 2006b). EF's face and body language providing, according to my perception, few cues to signal when he wants to speak or to give meaning to what he is saying, further complicate this. When he does speak, it seems an effort and does not seamlessly fit into the current conversation. EF appears to be both present and not present in space, his body language often not giving a sense of being engaged socially and to some extent physically in the space. EF said that his neutral body language is an attempt to fit in rather than to risk presenting the wrong body language.

This made it difficult to engage with him sometimes on the go-alongs, as I had no cues to invite me to talk. Even when sitting on the bus, where EF often instigated conversation, communication was difficult, due to the noise. As I sat alongside him, I could not completely see his facial expression or lip movements. Therefore we did not experience the usual back and forth of conversation and body language which creates a feeling of connection, providing cues as to initiating, maintaining and terminating what Goffman describes as 'states of talk' (Goffman, 1972:145). Accordingly, while I knew logically that I could start or finish a line of conversation, there was a gap, it may have been an emotional element that was missing. Having an emotional connection to EF and/or the presence of physical cues such as facial expression and body language would have provided the cues to encourage or deter me from making conversation. Shriberg et al agree with this suggestion, arguing that

how the listener experiences other's speech affects the listeners assumptions concerning the speaker's social-emotional state (Shriberg et al., 2001:1110). I suggest the establishment of an emotional connection is an important element of comfort in interactional space, discussed in later chapters.

This was also complicated by my role as researcher, trying to avoid asking leading questions, mixed with concern as to whether I needed to do anything to 'make' EF more comfortable so he felt more able to speak. Any attempt at establishing a rapport was often interrupted by the noise from the spatial context of the go-along, whether people, emergency vehicle sirens, or street noise. Another reason that may have impeded creating a rapport was that EF said he had never been able to grasp the rules of social interaction. He said part of this was because the noise of people talking is painful to him. This means EF prefers the Internet, particularly Facebook to communicate, part of his member checking of the data being carried out in this way.

EF: ignored in interactional space because it was easier to talk to his friend

EF's issues with speech resulted in people trying to talk to me instead of him. At the centre where EF volunteers, one of the workers questioned me very closely about why I was there with him, we stuck to our prearranged story that I was a friend, with similar interests. However, what we had not considered was that only one member of the group, plus the staff and volunteers came to session, instead of the eight expected, which would have made me less conspicuous. It became difficult to switch their attention from me to EF, as he did not give any signals of wanting to talk so they kept returning to me. It seemed there was a conscious or unconscious temptation to include me in their interactional space at the expense of excluding EF to avoid the effort of engaging him in two-way conversation. As a recent graduate in

the subject area, he was better qualified than the rest of us. However, despite this, they appeared happy to give EF instructions, which he carried out; otherwise, he appeared to be disengaged during most of the discussions. At these times, he appeared totally passive and distanced, as I would do if I were not being included. However, I can simultaneously present a measure of alertness to be ready to engage, without my being included, which he did not seem to have.

Analysis: EF: unpicking social exclusion

I felt excluding EF from interactional space was due to not wanting risk either side misunderstanding the other, creating embarrassment and a resulting loss of face (Goffman, 1972:9). From this, it is easy to see how typically developing people misread autistics if they do not present the expected social signals through body language and/or facial expression. EF's interactions could be read as ambivalence, or complete disinterest, however, getting to know him would have told them that he takes four buses in order to volunteer at the centre. During later discussions he said his lack of engagement was due to issues with short term memory, which complicated his difficulty in reading how and when to join the conversational flow, which is also discussed by Smith and Grandin (Smith, 2005). Poirier and Martin in their review of literature on short-term memory argue it is impaired in autism, although they are not clear whether it also affects verbal short term memory (Grandin, 2011; Poirier and Martin, 2008:245). The ability to store information in short-term memory is crucial for conversation, individuals, or groups often speaking for several minutes without a pause. While they speak the listener has to attempt to remember what each person has said to structure their response so that when they speak their views fit into the flow of conversation (MRC Cognition and Brain Sciences Unit, 2008). If, as appears to be the case with EF, short-term verbal

memory is impaired, this is compounded by working memory also being an executive function (Kalbfleisch and Loughan, 2011:123). This means both remembering and sequencing what he wants to say is problematic. For EF this a conscious process, that also involves trying to remember social conventions and remembering motor tasks such as moving his tongue to make the speech, hence EF says he gets very tired when he has to speak for a long time. This means he takes the considerable risk every time he joins a conversation that he will be out of step. Part of being out of step could also be because studies have shown autistics may not use inner speech to verbally rehearse what they wish to say (Poirier and Martin, 2008:240). Something typically developing people do preconsciously, before they speak.

This makes it easy to understand EF's reticence to join conversation and his anxiety, which increases his potential to stutter. Again resulting in a loss of face for him and the person who is attempting to talk to him. Shriberg et al argue that listeners have narrow tolerance ranges to define what is usual speech, which will be discussed in more detail in a later case study (Shriberg et al., 2001:1110). Misunderstandings may threaten those sharing space with EF and other autistics perception of their social competence, compromising their self-image, or membership of their reference group, resulting in defensive or punitive responses (Brown and Levinson, 1987:61; Shibutani, 1955). Something I have witnessed but not fully understood, in my role as a support worker. Misunderstandings threaten the harmony of interactional space, something people often wish to preserve even at the cost of excluding certain individuals. The staff's probable intention was as Goffma argues, to avoid causing embarrassment, in this case, by not speaking to EF, pretending there is no difficulty to protect his 'face' and feelings, however, the unintended consequence was EF's exclusion (Goffman, 1956:267).

This made my experience at the centre a stressful one, again the effect of interactional aspects, affecting my comfort in the social space of the encounter. I was frustrated that the staff and other volunteers did not relate to EF as an equal or recognise his expertise. This resulted in EF busying himself with various tools rather than taking part in the teaching.

Debra: A case of using a bear shaped rucksack, Bearsac, to challenge the status quo

Debra was keen to support this study because of her awareness of her issues with space. At her request, she is not anonymised as Bearsac, her diagnosis of Asperger's and other activities are well documented publicly (Aspiebear, 2011a; c; Dickinson, 2009; Schiman, 2009; n.d.).

Debra says Bearsac is a hobby, calming and stimulating her as necessary, and a tool for challenging social barriers. Debra with Bearsac, unlike EF and CD, will when she chooses, take over social space. However, in formal settings such as the meetings I attended with Debra in our role as trustees of the Developmental Adult Neurodiversity Association, Debra would most often be very quiet in a similar manner to both EF and CD, seeming not to know when to interact. When I checked this with Debra, she said it was because she was frustrated at the focus on detail in the various meetings and had nothing to add to the discussion, rather than being reluctant to join in.

This illustrates the important contribution of member checking, informed by the concept of the hyphen to ensure robustness of the data. During business meetings, Debra surreptitiously smelt or stroked the top of Bearsac's head, sprinkled earlier with lavender and other oils, if she began to experience sensory overload.[14] This helps her calm and refocus herself away from negative sensory stimuli.

When Debra spoke as Bearsac, she or he appeared to ignore many social inhibitions such as not talking to strangers. Her demeanour would have a similar flavour to that

[14] DEBRA refers to overload, rather than meltdown or shutdown.

of a group of women out on a hen night, their inhibitions reduced, exhibiting slightly unpredictable demeanour. This often breached ideological, contextual, elements of social space, but appeared to be accepted by many. This could have been due to Debra's gender, had she been a man, she may have been seen as more of a threat. In addition, her appearance and demeanour have a significant effect on how she is accepted; she appears young, middleclass, educated, fashionable, feminine, slightly vulnerable, and sexy. She is friendly and approachable, when I was with her, if her demeanour was slightly different it did not appear to draw any looks or comments. This often hides the turmoil that is often occurring in the physiological space of Debra's body, hypersensitivity to light, noise, and smell from the surrounding space leading to increasing tiredness, which can lead to complete sensory overload.

Debra: The effect of noise

The worst effect appears to be that of noise, an all-pervasive aspect of space, especially sharp, unexpected sounds. The extreme intrusion of noise into the space of her body from the surrounding space, means that unlike EF, she has no inhibition about putting her fingers in her ears, including repeatedly when she is walking outside. Debra is often in high profile settings, due to her work and social interests; despite this she still responds by putting her fingers in her ears due to the pain caused by noise, with no visible negative reactions from those sharing the space (Aspiebear, 2011a). I wondered whether Debra's readiness to do this has to do with gender expectations. When Debra puts her fingers in her ears and winces in pain, she looks vulnerable, fitting gender expectations of women and is no spatial threat.

Whereas culturally, men are not supposed to show their feelings or vulnerability; accordingly EF reports being vigorously discouraged from blocking his ears with his fingers at school.

Debra said the new police sirens were one of the worse noises, she could tolerate the old ‘Neenah, Neenah’ sirens but not the new American ones, which are painful even if she is indoors. I wanted to know if other autistics had similar experiences, so I compared Debra's experience with those involved in discussions on Wrong Planet, the online, autism discussion group (WrongPlanet.net, 2004-11). I found many responses, some said they sleep through the day to avoid noise and get quiet time at night (bonuspoints, 2010; jagatai, 2010b; SamwiseGamgee, 2010). The effect of noise was so great for one person they said that if they were forced to sleep through the night, their life would be ‘a headachy nightmare’ (SamwiseGamgee, 2010). Other Wrong Planet members said they use electric fans, industrial strength earplugs, ear muffs used for shooting and white noise to reduce the pain of noise (Element333, 2010; GumbyLives, 2010; jagatai, 2010b).

At one meeting we attended packets of potato crisps (chips) were provided. Debra said the noise of the packets being crinkled caused her pain, providing an example of how even a taken for granted daily object can affect autistics’ spatial comfort. Others on Wrong Planet describe the effect of similar noises that most of the typically developing population do not even register. For instance the repetitive noise of a cat licking themselves, which they say is amplified at night (bonuspoints, 2010; SamwiseGamgee, 2010). Another person described getting panicky when their father was coughing, which no matter where he was in the house, sounded as if he was standing right next to their ear (GumbyLives, 2010). Dogs barking and

lawnmowers are other sounds that cause distress (Dizzeh, 2010; GumbyLives, 2010). Another person paradoxically stated that the noise and motion from a nearby railway track that rattles their house does not disturb them. Whereas cars passing their house gives them a headache (bonuspoints, 2010). OP, a participant I will discuss later in this chapter is also affected by tyre noise. He says that improvements made to tyres' road holding ability has made them nosier and this is a huge issue for him as his only mode of transport is a bicycle. Another person, on Wrong Planet, despite having worked on the railways for many years, still jumps every time they hear a train horn (loko, 2010).

Debra also visibly reacted to certain voices if they were harsh, loud, or high-pitched, on Wrong Planet, loko, also says his niece hurts his ears when she talks (loko, 2010).

Figure 18. The coffee shop at the St Pancras YHA hostel photo: http://www.yha.org.uk/hostel/london-st-pancras

Boddart et al suggest that in autistic children and adults sensitivity to noise is associated with a ‘dysfunction’ of specific temporal regions, specialized in the perception and integration of complex sounds (Boddaert et al., 2004:2119).

On our first go-along Debra, Bearsac, and I meet at the coffee shop of the St Pancras YHA hostel in London. As can be seen in figure 18 above, it is a sensorially complex space. Debra uses the coffee bar regularly to meet people. Despite this, it appeared this was a very uncomfortable space for her. The extent of its physiological intrusion was clearly illustrated as Debra tried to describe the effect of the space on her. It appeared that noise was attacking her from every direction, causing her to wince and exclaim, other autistics describe similar sensations (autisticgal, 2011). If it was a really bad noise, she put her fingers in her ears, stroking and smelling Bearsac, this being her main strategy to overcome sensory overload.

Debra pointed out that noise was coming from a speaker in the ceiling, a nearby reception area, the people talking in the space, together with intermittent noise from the coffee machine and the street outside. Other aspects of the space that affected Debra’s senses were the many shapes, the curve of the counter, curves on the ceiling, the shape of the tables and chairs and the differing patterns on the walls and ceilings. Debra says she has a tendency towards becoming overly focused on pattern and detail. There were also many different forms of lighting, ranging from flush ceiling lights, with reflectors, to spotlights and overhead pedant lamps. Debra said that this kind of space causes a gradual overload, with a slow to medium build up which causes her long-term tiredness.

When I gave Debra my first write up of our go-along, the effect of other spatial intrusions became apparent as she shaded her eyes to block out the people passing

in the street, before she could read what I had written. The movement and the reflections they created on the window affected her. She was particularly distracted by a couple who were standing outside the window, one endlessly adjusting the belt of the other. The first time we visited the coffee bar, it was dark and light reflected off the windows creating all kinds of shapes and shadows, intensified by the reflection of passing car headlights. When describing the environment in this detail, it is easy to see how autistics come become sensorially overloaded. Debra said she was also affected by the smell of food, in particular, coffee and to a lesser extent meat. Many of the typically developing population experience urban spaces as an incidental background to their daily activity. They may experience it as more tiring than a suburb, but not as an immediately, multi-channelled, intrusive, physiological experience. When I first met KM who we meet in the next chapter, she said it was like living in the video music channel, MTV.

Debra: peripheral vision

Debra's overload is exacerbated by her enhanced peripheral vision. I noticed when was Debra was tired, she would shield one eye. When I asked her about this, Debra said she often looked out of one eye when she was stressed. She explained that closing one eye helps to shut out some of the information from her peripheral vision. Similar difficulty is reported by a parent who said their child liked to wear a hooded top as it reduces movement in his peripheral vision (Feature: your stress stories, 2011). Debra said that closing one eye also helps when she is speaking, as it improves her understanding of what the other person is saying, enhanced by focusing on their mouth as they speak. For further detail on visual sensitivity see Marco et al 2011 (Elysa J. Marco et al., 2011).

The effect of peripheral vision requires an understanding of how the eye processes vision using the retina, part of which is the fovea, both containing rods and cones. The fovea consists mostly of tightly packed cones, which are responsible for distinguishing fine details and colour, during daylight (Crick and Khaw, 2003:264). The periphery of the retina conversely consists mostly of rods, used to see in poor light. They have slower response rate than cone cells, leading to sensitivity to flicker fusion, hence Debra's sensitivity to light, and reflection (Crick and Khaw, 2003:264). Other autistics such as Williams, Smith and KM, on the other hand report having very good peripheral vision and less unified central vision (Smith, 2006c; Williams, 2007a).

Yoshida et al found that while there was no difference in the time taken to complete the tasks between typically developing and autistic children, the autistic children were more effective at using their peripheral than their peers. They concluded that the effective visual field of autistic children is expanded compared to typically developing children (Yoshida et al., 2011). Ben Shalom and Hadjikhani et al argue, it is not the physical structures of the eye that function differently in autism, but rather the neurological processes of the brain that prevent effective visual integration (Ben Shalom, 2011d; Hadjikhani et al., 2004:270).

Debra: mediation of social interaction

To move on from sensory concerns to Debra's functioning in social space. One of the few times I observed Debra 'speaking' through Bearsac was to a Korean woman. In the YHA café, in this instance social space was mediated by Bearsac. The Korean woman appeared quite happy to converse with Debra through him and they exchanged cards. When she left, she said goodbye to both Bearsac and Debra,

shaking hands, at the end of what seemed to have been an enjoyable encounter. Therefore making a connection which CD and EF had been unable to do with the solicitor and the woman giving CD directions. Debra attempted to speak to someone else through Bearsac, but they ignored her. Debra said this sometimes happens; she views it as a reflection of inflexibility of the individual rather than anything done by her and Bearsac. As we left the cafe Debra and Bearsac said goodbye to the whole café, which surprised me, Debra told them about her website and book. Most people looked at her and seemed interested in what she was saying. However, this was in a central London café, a more cosmopolitan social space than the affluent suburb where she lives, which I will discuss later. In the cafe, the positive response was probably partially due to Debra's appearance and demeanour.

Debra looks and to a fair degree acts like any other ‘female office worker’. She makes a lot of her own and Bearsac’s clothes, they are fashionable, as is her hairstyle; she might appear ‘forward’, but no more than any other young woman in her apparent age group. Debra is older than she appears, giving off cues that place her as young, middleclass, fashionable, possibly in admin or advertising. To this extent, she consciously manages her social persona unlike OP, who I will discuss later, to promote her book and web presence.

Therefore, apart from when Debra speaks through Bearsac, she attracts little interest and if she does, it is largely positive as evidenced in a YouTube clip of her on the Paris Metro (Aspiebear, 2011b). This allows her to travel extensively overseas. Debra says that impact of Bearsac on her social and interactional space is considerable, speaking through him breaking down barriers for those meeting her, rather than making it easy for her to speak (Schiman, 2009:iv). If Debra makes a

social mistake, it is Bearsac who is at fault rather than her. In *Send In The Idiots*, Nazeer describes his school friend Andre, using his puppets in a similar way, to articulate his thoughts and ease social interaction (Nazeer, 2006-52). When I considered my surprise at Debra taking over the cafe as we left, I was reminded of Arnold's statement of there being an element of theatre about certain autistics' demeanour (Arnold, 2007).

One of Debra's longer YouTube videos*, 'Bearsac', Asperger's Syndrome Documentary UK* comprehensively illustrates her functioning in interactional space**.** It is important if you decide to watch this video to realise that it is edited to highlight Debra's concerns. Otherwise, the film could give you the impression that she is constantly accosting people with Bearsac, which is not the case. In the video, Debra visits shops, the market, and talks to people in the street through Bearsac. Debra says she finds it hard to read people and this is evident in the video. Here on occasions she imposes her wish to interact on them, without judging whether they were likely to be receptive to being spoken to through Bearsac. 'He' can be quite risqué at times, flirting, and making jokes. Debra portrays herself as his mummy and excuses his behaviour by saying he is very naughty sometimes.

In the video Bearsac got a very good reception from a woman in the supermarket, however, in the street, some people were reticent, one woman responding very negatively. It may have been that people were more reticent because they were being filmed, than if Debra and Bearsac had been on their own. The interactional space created by Debra and the woman, became one of heated debate, as the woman argued with Debra to the extent of ignoring that her baby, who seemed to like Bearsac, was crying. Debra pointed this out, but the woman dismissed the crying

baby, so engrossed was she in her verbal battle with Debra. At one point referring to Debra as the ‘nutter’ (sic) of her town. Debra pointed out the baby was crying several times, asking the woman why she did not comfort the baby instead of arguing with her, an example of the directness of autistic communication (Dickinson, 2009).

During this episode, Debra was slightly incongruously dressed in a Mongolian deel, whereas in the supermarket she looked as she usually does, fashionable, but relatively conventional. This may have had something to do with the woman' in the street’s reaction to her. The video got many responses on YouTube, twenty-six positive and seven negative. The negative comments mostly related to people who felt the contextual rules of social and interactional space had been infringed, as they would not like being accosted by someone they did not know in the street. One person felt the woman with the baby was right, and that it was more respectful to Debra to point out that it is ‘socially unacceptable’ to accost people she does not know with her’ teddy bear’ and ‘frighten them’. This person felt that those who joined in and talked to Bearsac were patronising Debra.

Pursuing similar arguments many of those who support autistics and others with a social disability, try to limit activity that appears out of the ordinary or 'draws attention to them’, arguing it 'puts them at risk’. However, from reading Debra’s books and watching her videos it is clear to see that Bearsac has allowed her to navigate problematic ideological, contextual, and sensory elements of social and interactional space. This has allowed her to relate to people of many cultures, from the USA, Europe, Sri Lanka, and Europe to Mongolia, being the most widely travelled of any of the participants in this study, despite severe sensory issues (Schiman, 2009). Some of those who left positive comments about the video, thought that Bearsac made it

easier for Debra to communicate, although as I said previously Debra says it allows others to more easily communicate with her. However, Bearsac is viewed he supported Debra, and those sharing space with her to interact.

OP: a case of perplexing presentation

The next case I present is that of OP, who takes over space, in a different and more subtle way than Debra, which is difficult to quantify at first glance. OP is friendly, highly intelligent, but always slightly out of step with the ideological and contextual elements of the social and interactional space and those around him. He nearly always does not quite manage to tune into difficult to define, nonverbal, nuanced, context dependent, socio/spatial rules, for instance Sapir's 'elaborate and secret code' (Barker, 1968:19f; Bourdieu and Nice, 1977:72; Giddens, 1984:4; Sapir, 1927b:137). OP unlike CD, EF, and Debra (without Bearsac) talks a lot, often not picking up whether others are interested in what he is saying. He is a prime example of someone who we know is out of step, but how is only partly lodged in our consciousness and therefore difficult to articulate. In OP's case, his demeanour meant that he drifted into participation and consented to inclusion.

I will illustrate the effect of this on social and interactional space by describing a go-along to the coast with OP and his friend. On the train, the three of us sat facing each other, his friend was a few years older, and looked like an average middleclass, male, I, a middle class, female and then OP who is a few years younger than I am. OP is very fastidious; he was dressed in clean, functional clothing, well worn, but not faded sweatshirt, trousers, and trainers. Very unremarkable, his appearance providing few cues as to who he is. When relaxed OP has an air of innocence, like many autistics, including Debra and KM, looking younger than his age. There is no suggestion of class, occupation, marital status, or even age in OP's appearance; whereas it was obvious, his friend was a middle-aged, middle class professional. His friend and I passed without notice. However, throughout the day, on the various trains and buses, I was struck by how many people openly stared at OP. OP said he

was aware of this, but did not seem too concerned. I may have been more aware of this as OP spoke to his friend most of the time, giving me the opportunity to observe others' behaviours, which was limited when I was one-to-one with other participants. The reason for people staring puzzled me while I was writing this case study. The most obvious thing seemed to be that we were often in confined spaces, followed by people trying to pin down who OP was from his appearance. In this example unlike CD and EF, OP was affecting contextual aspects of space to a greater degree than interactional aspects.

His friend and I were not perturbed, by OPs spatial demeanour in the interactional space we created around us, whilst those in the wider social space around us were continually drawn to OP. Why was this? I returned to Goffman's work and realised there is a dissonance between the expression that OP gives through speaking and the expression he gives off by his behaviour (Goffman, 1990:14).

In this case, OP's highly technical discussion of radio frequencies was at variance with his appearance of naivety, and one-sided conversation with his friend. These contrasting inferences, cause many misunderstandings within OP's social space for instance his living arrangements, but not to the extremes experienced by IJ and MN. This is compounded by differences in prosody, which I discuss later, which Peppé et al argue may confuse the listener, leading to misunderstandings (Peppé et al., 2011:42, 51).

OP: talking as if to a child not an adult?

The confusion caused by his appearance and demeanour was illustrated at OP's mother's funeral. He is a very talented classical guitarist, although he does not play publically. After his performance, the vicar said ‘well done OP’, in similar way to

congratulating a child, not a talented musician. Reed and McIntosh highlight important role of social, emotional, and postural cues in connecting to others and their role in our understanding of who the person is, what they are doing, what they intend to do, and how we should respond to them (Reed and McIntosh, 2008:80,82). Uncertainty about how to respond to an individual creates spatial tension. An integral part of preventing spatial tension, Goffman argues, requires those we meet guiding and controlling the impression they give to us. OP is unaware of the need to introduce or establish his presence, providing no clues as to who he is or how to respond to him, in the absence of these cues the vicar treated him as subordinate (Goffman, 1971a: para 2).

OP: further thoughts

Returning to the train, if someone stared at me, I might adjust my language and posture to give them enough information to satisfying them as to who I am, and if I did not like their response, I would readjust it again to get the response I wanted. However, OP appeared oblivious to the staring and made no response.

It appeared that it was not just OP's appearance that was attracting attention, which puzzled me as I searched for a cause. Eventually I considered OP’s speech, which seems different, although until I began this study it was not clear why. When his friend and I spoke, very little of our conversation appeared to disturb the social space beyond the space of our interaction we had created in the larger space of the train carriage etc. Whereas, OP’s voice although very slightly louder, extended beyond the interactional space of his conversation and apparently disturbed the social space of those around us. This appeared to be amplified by the dissonance between what he was saying and his appearance. ZA, another participant in this study, appeared

clumsy, argumentative, and loud, but did not get stared at or if people did it was done surreptitiously. I concluded this was because ZA had a more visible disability, possibly accompanied by the erroneous assumption of a learning difficulty. Whereas with OP, people would look, then stare and go back to what they were doing, then his speech would again intrude into their interactional or personal space, and they would stare again.

In Op's case, I consider that there are two aspects to this. The first is that the content of OP's conversation does not follow some of Grice's maxims of speech, do not say more or less than is required, be relevant, and avoid obscurity (Grice 1975 quoted in Brown and Levinson, 1987:95). Because OP was not following these his dialogue unsettled the surrounding social space.

OP and the elusive effects of prosody

The other passengers probably concluded we were on a day out from our casual dress. They probably found OP's detailed conversation out of context, too long, and detailed, affecting their personal space in a way they could not quantify due to the unsettling effect of usually unarticulated rules of prosody not being met. Attempting to quantify what was drawing their attention, led me to Paul et al, who suggest autistics' prosody of speech almost immediately creates an impression of oddness or difference (Mesibov 1992 and Vanbourgondien and Woods 1992 quoted in Paul et al., 2005:205). Peppé et al argue that typically developing people are often unaware of the contribution of the effect of others' prosody on the assumptions they make about other's demeanour, because they do not correct their own prosodic errors (Peppé et al., 2007:1016).

Roach states the functions of prosody include:

> …verbal punctuation or phrasing; the expression of feelings and affect by intonation and tone of voice; indicating utterance-type, i.e., whether a conversational utterance is a question, a statement, or an invitation to continue speaking; and signalling the focal point of an utterance (Roach 2000 quoted in Peppé et al., 2011:42).

These functions affect the rhythm, loudness, pitch, and articulation rate of speech. They vary according to the speaker and their regional linguistic styles, which are not well-defined and are seldom made explicit (Peppé et al., 2011:42). There is a sense, Peppé et al argue, that prosody can be wrong or unusual, rather than there being any kind of verbally articulated ‘prosodic rules’. Before I read their paper, although I was aware on some level that OP’s verbal communication differed from the norm, I could not identify how, which is unsurprising as Peppé et al say this is a largely preconscious process (Peppé et al., 2011:42). Preconscious processing requires integration at Ben Shalom's level 2, which as she argues is difficult for autistics and makes attempts to verbally articulate ‘prosodic rules’ to assist them problematic (Ben Shalom, 2009:589f).

When I started to apply my new understanding of prosody to OP, I realised not only does he speak slightly louder than everyone else, at length, and without including them, but his voice is more intense and his pace of conversation slightly faster than others. This trait is also discussed by, Hobson who describes this form of presentation as a kind of monologue, spoken from the speaker’s perspective alone (Hobson, 1995:170). Whereas Goffman states that socially the individual is obliged to orientate their conversation so others can join it (Goffman, 1957:49). This

obligation is balanced by the speaker's right to expect others be interested in what they are saying (Goffman, 1957:49). In OP's case, on this occasion, this two-way negotiation did not occur often, as he spoke in a continuous flow making it difficult to ask questions.

I was also aware that I sometimes lost the thread of what OP was saying. I put it down to lack of knowledge of the topic of conversation and difficulty in paying attention for an entire day. In addition, that OP was both slightly nervous and excited by the day out, and the presence of his friend and I. However, my difficulty in understanding may have been due to OP's different verbal phrasing and punctuation (Peppé et al., 2011:51). I realised I sometimes have a similar difficulty with KM, knowing I should easily be able to understand what she is telling me, as we share similar interests, but occasionally unable to follow thread of the conversation, for no apparent reason.

Continuing to explain the effect of prosody, I return to our visit to the coast. On the train, a man sitting on the other side of the carriage kept looking at OP, OP's friend and then me. He would turn away and then after ten minutes or so would look again. With my new awareness of prosody, I realised in addition to being slightly louder and often a near monologue, OP's speech is distinctive because he applies emphasis arbitrarily to different parts of his speech, rather than to make point or add meaning to what he is saying. Instead, adjustments to emphasis and pace of speech are applied haphazardly, especially when he is making an important point. Because of this, his voice carries, its loudness and haphazard prosody intruding on other passengers' interactional and personal space. The personal space of those on trains and buses, particularly in British culture are locations of Brown and Levinson's

negative politeness, where, people wish to assert their right to a 'territory' of 'non-distraction' and 'freedom from imposition' (Brown and Levinson, 1987:61). Therefore, whereas OP's friend and I talked so we could hear each other, we did not intrude on others' space to the extent it drew their attention, whereas OP's did, perhaps intensified by the confined space.

This may have be one of the reasons why people stared all day. One woman on one of the buses looked very hostile when OP went to sit next to her, whilst simultaneously giving his friend and I, a lengthy recitation of the bus timetable and all the possible routes we could have taken, as he explained which bus we needed. Part of the reason for this could be that OP regularly provides a running commentary on what he is doing. However, on this occasion it could have been due to nervousness at having his first outing with me than autism.

Witnessing the profound effect that prosody has on social and personal space, led me to question why we are not aware of its effects. Peppé et al suggest this is because it is not perceived as having a significant role in communication. This means prosodic errors are not corrected by carers during language development, whereas poor pronunciation and choice of words are (Tarplee 1996 quoted in Peppé et al., 2011:2). I suggest another reason for the lack of attention to prosody during language development, which returns us to Ben Shalom's work, is that it is largely preconscious. Hence, my difficulty in articulating why OP was attracting so much attention.

Other autistics also discuss differences in prosody. During discussions on Wrong Planet, people describe various issues such as having English accents when they have always lived in America or New Zealand for instance. Others say that people

comment that they sound idiosyncratic, monotone, stilted, sing-songy, robotic, deep, or pedantic. While others say autistics' prosody makes them sound too enthusiastic or that they do not care (WrongPlanet.net, 2008c). In OP's case, I would say none of these descriptions really fit him. This adds to the difficulty in understanding why his speech attracts people's attention.

OP: a case of the paralysing effect of noise

On another go-along, OP and I were in the gardening section of a large chain store, chatting happily about the goods on display, when OP's voice suddenly became tense and agitated. Simultaneously, in an instant his face turned from being animated, full, with a light-hearted expression, to his skin stretching out and hollowing over his cheekbones. Superficially, he appeared angry or aggressive.

The speed at which this occurred was disturbing, leaving me with a sense of powerlessness on one hand and a query as to whether I should take some kind of action. The most accurate description I can give is my emotional response that OP felt out of control. This threatened me to some degree especially as he accompanied his expression by saying, 'that's what I can't stand, that's what I can't stand' in a tone that appeared to be aggressive. In hindsight and after his explanation below, I realise his reaction was a mixture of fear and panic, which transferred itself to me but not on such an extreme level as OP. What he said seemed out of context, as I could not sense anything had changed or what was wrong. However, as his arousal subsided he said it was due to the noise of someone's high heels on the hard floor of the shop. OP explained this was very uncomfortable, the rhythmic noise of high heels hitting the ground, paralysing his mind so he could not think. He said this paralysis also results from other rhythmic noises. This causes panic because whilst hearing these

noises he feels out of control of himself and his environment. He said high heels were the noise he hated most, crossing the street or going into doorways so the person wearing high heels will pass him, as he cannot 'think' during the noise.

OP: analysis

Here we see the beginning of the harnessing of my emotional reactions and sense of spatial comfort to understand how autistics and typically developing people affect each other within social and interactional space. The effect of similar emotional reactions to mine in response to OP's distress to was brought to my attention by KM, who we will meet in the following chapter. She says something that is a logical issue for autistic people, is often quickly turned into an emotional one by typically developing people, affecting the spatial comfort of both. The autistic person becomes confused because they perceive they were stating a fact; partly due to using logic at level 3 to compensate for lack of integration at level 2. The typically developing person using preconscious integration, however, adds an emotional element to the event that autistics often do not comprehend. In this case, I suggest it is because of the ease with which fear can be read as aggression by typically developing people as illustrated in figure 20 below:

Photo: http://confident1.com/how-to-be-assertive

Figure 20. Which is fear and which is anger? The two could appear very similar in the heat of the moment, how does someone, for instance a police officer distinguish which is which?

Photo: http://www.eft-downloads.com/FearPhy.asp

Many other noises affecting OP were similar to those that affect Debra, noises with a beat or that are repetitive. We heard examples of these noises on our way back from the shops. They included the beep on a pedestrian crossing, the residual beat from passing car stereos, music from someone's garden, even though we were the other side of the park, and tyre noise on the road. OP says tyre noise has got worse as the road holding capacity of tyres has improved. So acute is OP's hearing that when we were on the train to the coast he told us one of the wheels on the carriage had a 'flat' where its brake pad had seized. He only goes to certain restaurants, which have no echo, when I remarked that these restaurants had no carpet; he said that the wall coverings in one restaurant and the beams in another were enough to dissipate the noise.

AB: a case of alternate hyper and hyposensitivity to noise

I met AB at a conference where I shared my research and he expressed interest. He is a professional musician, playing as often as he can in public and regularly attending the concerts of others. He is a music graduate in his late twenties. He tolerates the very loud noise of the organ, but not the music of ice cream vans, to the extent of being able to recite the legislation governing the use of their jingles. In a similar way to OP, he says the jingles and other sudden noises shatter his concentration, although the effect of this was not as apparent as when I was with OP.

However, unlike many participants in this study who do not outwardly show signs of internal physiological discomfort, AB does, often using large movements to stretch his limbs, because he is very uncomfortable. AB also burps, sneezes and coughs more than others do which disrupts the personal space of others. AB like many other typically developing men of his age often said he was irritated by others' criticism and the difficulty in negotiating friendships with both sexes. Apart from his need to move he was vague about any spatial issues, he might have. This meant I had to rely to great extent on my observations, checking them with him during member checking, being more directive than with other participants.

The effect on others of his burping, other noises and stretching was evident at the first concert I attended with him. When we sat down, he did a cross between a snort and a loud sneeze, which could have caused a woman who was already sitting nearby to move to another section. The concert was attended by serious followers of classical organ music, perhaps making her less tolerant of any interruption of her enjoyment. However, once the music started AB followed his music score, only

moving to turn the pages. We sat, a few feet from the organ. The noise was extremely loud, as was AB's clapping, which sounded like a gunshot at each clap. During the interval he stretched his arms across his chest, and flexed his legs several times using large movements. This included rubbing the back of his wrists several times on the edge of his seat. AB said he was trying to get the circulation in his wrists going and the muscles in his arms and legs were aching and this is a continual problem.

AB: Analysis

Later when we discussed the evening, I mentioned the woman moving, he had been oblivious to this, laughed and seemed unconcerned. He said people had told him he snorted and coughed louder than others, he did not seem to mind being told, as long as it was not constantly made an issue. He said the reason for his loud sneezing, snorting and coughing is that his nose runs in winter and gets blocked in summer and he is unable to find a satisfactory treatment. He said he stretched a lot because he had discomfort in the muscles of his legs, back, and arms and this helped.

Jetson says he thinks proprioception is the driving force behind his leg-movements, which he describes as stimulatory, when he is sitting at a desk for a long time, the movement helping to reintegrate his body sense (Jetson, 2011). The chadmaster says he loses sensation in his arms, fingers and toes if he is not actively using/moving them, similarly Civet says he/she keeps finding themselves rubbing their arms and legs (Civet, 2011; thechadmaster, 2011). Williams says when she was young she needed to keep moving something otherwise she would lose the sense of her body in space (Williams, 2010). Fleishman says she cannot sit still

because her legs are on fire and it feels like ants are crawling up her arms (Goldberg and Putrino, 2009).

Whilst AB does not talk in a such dramatic way I noticed that when we were walking AB often paused slightly scratching the back of his calf with the front of his opposite foot. He said it was because his calf itched, other autistics also report itching sensations although more severe than AB seems to experience (WrongPlanet.net, 2011). When he is in the street AB says he often overtakes people and then has to pause to scratch his calf with his foot exasperating those behind him.

AB: a case of seeking rather than avoiding stimulation

I also noticed AB sniffs books or music scores when he first picks them up. On another occasion when we met for a coffee, I noticed that every so often he randomly touched some of the items on the table. Others on Wrong Planet describe touching things, because they like the feel of them (WrongPlanet.net, 2012b). With AB he just continually touched things, and people but not in a 'touchy-feely' way. In the case of people, he would put out his hand to do a variation of a high five or handshake, not just as a greeting but sometimes to punctuate the conversation, for instance if he agreed with something I said; I wondered if he was seeking sensory feedback. When I suggested this to AB, he was non-committal; it seemed to be something he did, in a similar way to someone fiddling with clothing or hair, although more often. I considered this was at variance with AB’s appearance, which unlike OP's is not ambiguous, nor does he look like one of the lads as EF does. But rather as a middle-class, bookish graduate, which others may think accounts for his differences in demeanour.

Chapter 4: Long Case Study

Section 1: Sensory issues: KM a case of extreme lack of visual integration

KM	Mid forties, multi-talented, well on her way to the top of her profession	Type 1 Severe sensory issues and apparently less severe social issues

In this chapter, I will present the narrative and analysis of data gathered from go-alongs and discussions with KM who appears to fit Ben Shalom's Type I. However, she could also fit into Lane et al's sensory modulation with movement sensitivity subtype (SMMS), having sensory processing issues in all sensory domains, plus low energy and poor endurance (Lane et al., 2010:119). KM has extreme sensory issues affecting her perception of and functioning in space. However, she is more socially successful, than the previous group through extensive use of compensatory strategies, at the expense of huge demands on her stamina. Within the overarching case study frame of this study KM is an outlier case being the only participant who appears to be Type I. I attempted to recruit others who appear to fit this type, without success. After discussions with KM and others, I concluded many of this group could be so overwhelmed by their surroundings they have no energy for anything else or cannot access the world beyond their immediate surroundings (Ben Shalom, 2011b; Murray, 2009). This means KM's data offers us a unique insight into their experience. As time went on other participants appeared to have some similar experiences; however, it was not possible without asking leading questions to

discover this. This is one disadvantage of employing unstructured, user-led interviews. However, I am of the opinion this outweighed by the ethical and methodological rigour enforced by other aspects of my research frame, such as member checking.

I first met KM when I was presenting conceptual design models, demonstrating how various settings could be made sensorially accessible. I invited comments, and KM joined the discussion. Since then KM and I have been in contact, through e-mail, text, and phone. KM had the most involvement in this study, providing extensive data, and lengthy discussions regarding her experience. This included feedback on the factual content and structure of this thesis. KM is a middle-class, middle-aged professional woman with a successful career. During this study, we created a close working relationship and friendship. At first, this concerned me, in my previous role as a social worker I always maintained a professional distance, especially with those perceived as 'vulnerable'. However, the close working collaboration I formed with KM was highly productive. In Barkaoui et al's study concerning changing cognition in older people, similar fruitful, mutual, long-term friendships developed (Barkaoui et al., 2011:64). They argued this enabled them to focus on the 'microgenetic' details of the participants' functioning (Barkaoui et al., 2011:63). Oakley makes a similar observation in her study with pregnant women, suggesting that research 'about people' is only successful if the researcher invested in the relationship (Oakley, 1993:229).

KM has issues processing all elements of space, physical and ideological affecting her functioning in interactional, social, and virtual space. During our contact she demonstrated her issues in processing and integrating information at level two in the

four domains of motor, emotion, memory, and sensation/perception described by Ben Shalom (Ben Shalom, 2009:589f).

Firstly, I will look at KM's account of her perception of space and objects. She sums this up by stating that:

> my senses are so disordered that as a
>
> child i used to feel locked _behind_
>
> my eyes[15]

KM says her motor and visual performance are at the level of a typically developing, nine month old baby, described by Winnicott as existing comfortably in a ‘drifting stream of unintegrated moments’ (quoted in Mitchell and Black, 1995:125). Gepner and Féron argue along similar lines stating that autistics may live in a space '… like a puzzle of static pictures with no in-between relations' (Gepner and Féron, 2009:92). Ben Shalom suggests in this state typically developing infants respond to external stimuli, rather than initiating their own responses (Ben Shalom, 2011c). The world coming to the baby rather than the other way round; the baby responding instinctively at Ben Shalom's level I (Ben Shalom, 2009). Gerland, an autistic

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[15] You will notice that the emails between KM and I are very brief. This style of communication, a line at a time, with no salutation at the beginning or end of the email, is KM’s preferred way of communicating as it needs less energy to process. Williams also says she processes best when as few words are used as possible with a separate line for each point (Williams n.d.-a).

woman, says that as a child ‘visions did not come to her’ she had to ‘fetch’ them from her eyes (Gerland, 1997:65).

Therefore, in this case, KM’s major concern is how she visually and physically perceives and interacts with space. This differs from AJ and MN, whose major concern is how they are in the world, i.e. how they manage the social elements of space, through their demeanour and their homes as workplaces for support and other workers. KM also differs from other participants due to major issues with visual integration and motor planning. However, KM has a greater sense of others’ emotional states, reducing the effects and visibility of issues with social processing. The other participants did not appear to have issues with visual integration and planning and all had fewer sensory issues. KM’s perception of physical space:

‘It’s full of stuff and most of it hurts’

My first discussion with KM concerned her motor planning issues. She says she can process the set of the children's TV programme, Teletubbies as it is made up of simple shapes and colours as illustrated in figure 21 below (BBC, 2012):

Figure 21. Teletubbyland. Photo: Ragdoll Limited

KM said this is because her visual perception has not developed beyond the target age of the program, of one to four years. Here it is important to distinguish between being able to see and being able to process what you see. KM can see, but cannot intuitively process what she sees.

The following gives an account of this:

KM says she can process squares, circles, and triangles. My supervisor was sceptical, arguing that shapes change depending on the viewing point, using the example of his desk. I e-mailed the picture of it in figure 22 to KM. Her response was that she groups ellipses and circles in the same way parallelogram is used to describe rhombuses, squares, and rectangles.

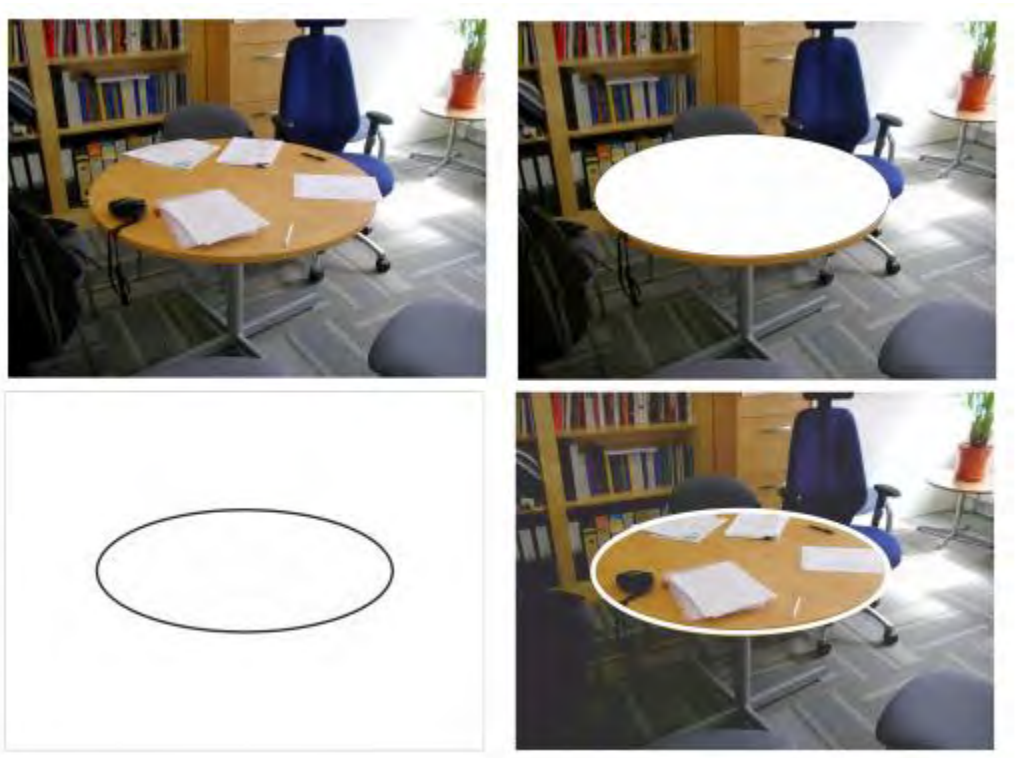


Figure 22. Table in my supervisor's office illustrating how objects change shape depending on the viewing point.

KM says she can most easily process natural environments as they are made up of ground and sky. Where there are plants and trees, they form a random pattern so she does not have to visually integrate them as illustrated in figure 23 below:

Figure 23. KM says natural environments are random therefore easier to process. Photo. www.mass.gov

KM used the example of her bedroom at a conference we were attending, to illustrate how her lack of spontaneous visual integration affects her daily spatial interaction. She said she organised her space to involve as little movement as possible. For instance deciding whether to keep the window open or shut for the whole of her stay, as it would take too much processing to keep adjusting it.

KM's perception of objects

The reasons for minimising movement quickly became apparent. Still in her bedroom, KM described how she perceives objects and how this affects her use of space. KM says that rationally she can name and recognise objects. She used the example of the chest of drawers in her bedroom; an illustration of a similar chest is in figure 24:

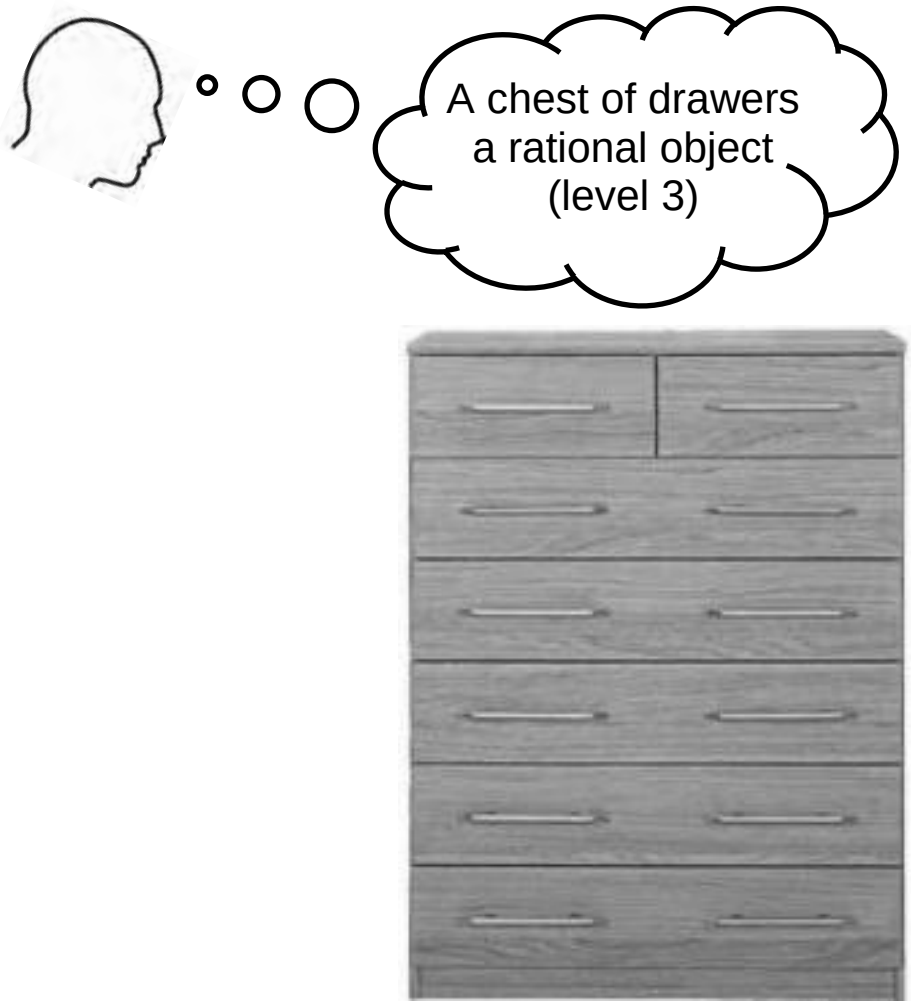


Figure 24. A chest of drawers as a rational object. Photo: www.argos.co.uk

She can recognise it as a chest of drawers but when she sees it for the first time, it is a disunified heap of ‘perceptual objects’ as illustrated in figure 25.

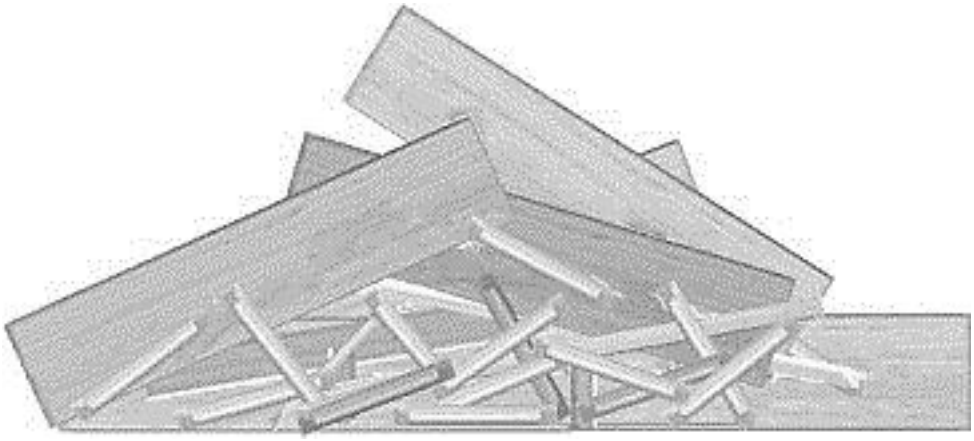


Figure 25. Disunified objects.

She perceives parts, rather than 'wholes' which the typically developing population preconsciously integrate to form unified objects (Ben Shalom, 2009:589f). Later, KM said if she went to an unfamiliar supermarket she would see the equivalent of a pile of bricks, she would have to group these into simple shapes and colours using logic (Ben Shalom, 2010). Applying Ben Shalom's integrative theory, KM unconsciously perceives perceptually defined parts of objects at level 1, whereas the typically developing population would preconsciously integrate the parts of objects at level 2. Instead, KM describes using logic at level 3, as a compensatory strategy to work round her lack of integratory skills, to consciously construct the chest of drawers like a jigsaw puzzle to create a unified object. KM says her visual processing is similar to that of Donna Williams who describes being given a doll's house, which she took apart and sorted into its different components having no conception of it as a whole, functional, object (Williams, 1998:20). Similarly, Williams describes asking for a toothpick and only being able to perceive a clear cylinder with a dome on top, filled with 'long, thin pieces of pointy ended wood' but no toothpicks (Williams, n.d.-b). van Dalen and Mukhopadhyay have similar experiences; Mukhopadhyay says he

perceives a fragmentary world through isolated sense organs (Boucher, 1996:84; Mukhopadhyay, 2000:73).

Even if there is a small change to the arrangement of familiar spaces KM has to reprocess it. Rand provides an example of this and its effect on his processing:

> So if someone learns that a picture hanging on a wall usually hangs straight, if they see a picture hanging straight, that information is easy to process because it is the same as before. It goes along the same pathways to the same places, maybe those places are checkpoints that decide what the information means. Like it is flat, it is colorful, it is scenery, it is hanging straight on the wall. So it gets to the same result. It is a picture. But if a picture is hanging crookedly, it might start being processed along the same pathways to the same checkpoints, but then it might suddenly stop at some checkpoint because something is not the same as before so some checkpoint made a different decision about the information. Then the information might go off that pathway along different pathways, and whenever different pathways have to be used they could turn out to be bad ones, which means the information could just stop completely or get backed up or go off on wrong pathways. So it might never get to the same result, that it is a picture, or it might finally get there, except that it took longer and was a lot more work (Rand quoted in Donnellan et al., 2006:225).

Brock et al provide a possible explanation for this, suggesting that in autism visual integration is impaired because local, specialized networks in the brain, process information in isolation. They argue this leads to a breakdown in integration caused by deficits in temporal binding between local networks, known as hypocoupling

(Brock et al., 2002:220). Ben Shalom uses a plate to illustrate this. She says typically developing people see the object as a whole, whereas some autistic people see something round in shape and white, before they see the whole (Ben Shalom, 2005:644).

KM says that every time she encounters a new object or new surroundings she has to use compensatory strategies to unify them. She regularly visits her mother's home and providing nothing is moved she does not have to reprocess it. This is because she is operating at Ben Shalom's level 1 using habit and perceptual memory to remember the layout (Ben Shalom and Clemerson, 2011). However, she rarely goes to the main street of the town where she lives because of the moving layouts of the shopkeepers' products and signs on the pavement[16]. When KM temporarily moved to a new town, with older buildings and bylaws against placing objects in the street she found she was able to navigate its centre.

One result of constantly having to use logic to combine parts of objects into wholes is that KM has the minimum of clothing and does not fold and put her clothes away as this takes up a huge amount of processing. Later KM told me she only has plain coloured clothing. This is restricted to certain colours, Prussian blue, cream, black and natural beige. As KM does not use drawers or closets, her clothing is heaped on the floor. This is not such a problem as it might sound as KM has only two sets of clothes, a long sleeved t-shirt, tracksuit bottoms, which she wears at home and a pair of jeans, long sleeved cream t-shirt, black jumper, and waterproof jacket, which she wears outside the home. KM says if her clothes were patterned or a mixture of

[16] sidewalk

warm and cool colours, the conflicting colours and shapes, heaped on the floor, would be painful to look at and take a great deal of energy to process. See figure 26 below illustrating the difference between warm and cool colours.

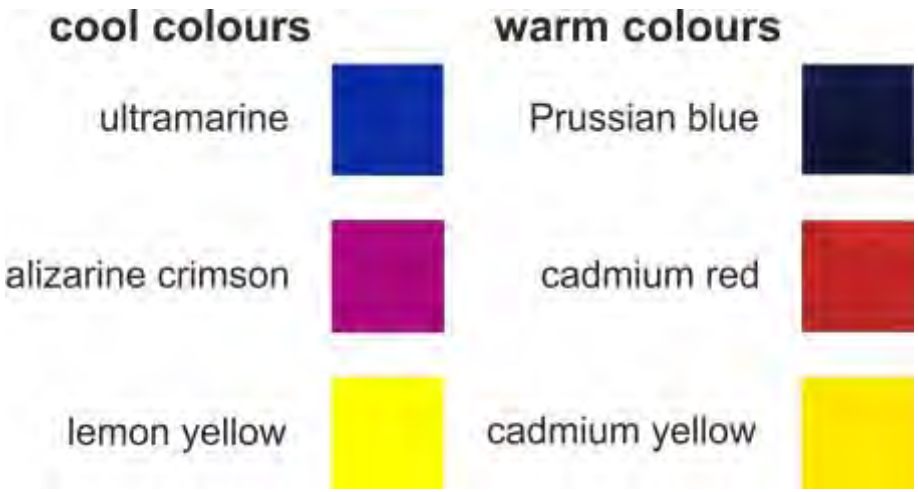


Figure 26. Warm and cool colours.

KM's differences in processing colour were illustrated when we went to a restaurant with a domed ceiling, the flat part of the ceiling and pillars were a warm cream and the inside of the dome was a cool white. KM pointed this out, saying it created a commotion in her mind that she could not resolve, making the space uncomfortable, affecting her enjoyment of the meal. CD also pointed out the jarring effect of mixing cool and warm colours to me in another shopping mall.

After our first meeting, I e-mailed KM pictures of different chairs asking whether they were easy or difficult to process. KM found the chair in figure 27 below difficult to process because of the curves, because she had to break up the planes into small flat pieces to attempt to process them.

Figure 27. Chair with curves is difficult process. Photo: Milanodirect.com

I also showed her the picture of the white chair in figure 28 below.

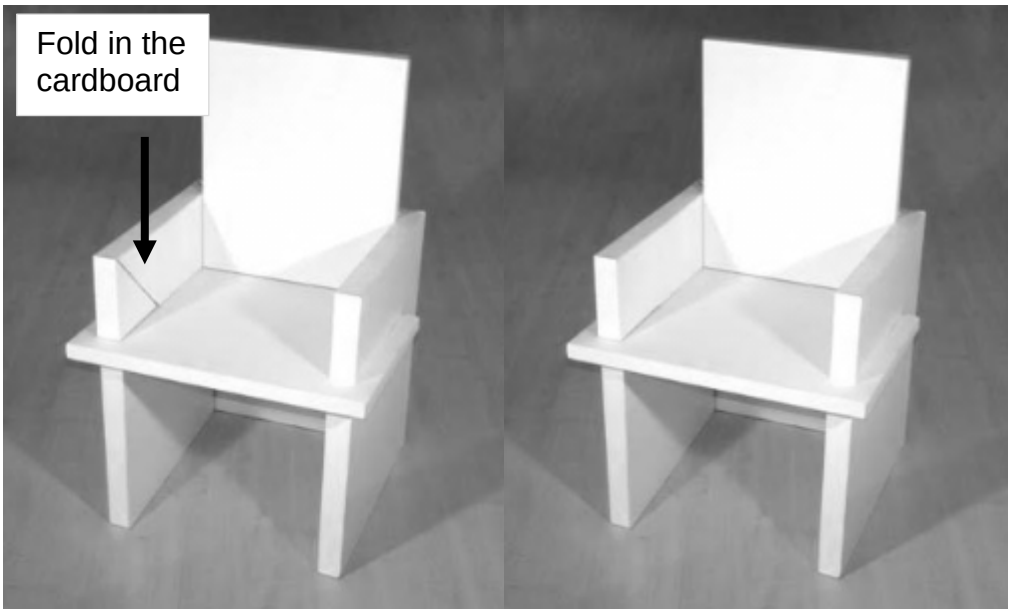


Figure 28. Picture showing the chair that should have been easy to process and the left and the picture on the right with the line removed which was causing difficulties in KM's processing

KM said that the chair should have been easy to process, as it was made up of flat planes with no curves. Yet somehow the chair was visually uncomfortable. After some thought I spotted the fold in the cardboard which I removed using Photoshop. KM said that without the line object was easy to process. My view is that such a

small detail which causes discomfort and distraction is important information for all those who share their lives with autistic people. This could have been missed by less person centred methodologies such as testing or questionnaires.

I then emailed the picture of the interior of the British Library shown in figure 29 below.

Figure 29: Interior of the British library, the curves created by the stairwell are on the far right of the photograph. Photo: Galinsky

KM said that most of the space was not uncomfortable, even the lights. However, the curve on the balcony caused discomfort because she could not process it, so the shape remained unresolved in her mind. KM said if she was in the space her brain would ask her all the time whether the curve was a circle, square or triangle. This fits Ben Shalom's account of the three levels of processing. KM perceiving the curve at

level one as a perceptual object, but not preconsciously integrating the curves into an integrated object at level 2 (Ben Shalom, 2009:589f). I also showed KM, what was to me, very complex picture of Somerset House, London shown in figure 30 below.

Figure 30.Somerset House. Photo: zafferano.co.uk

However, KM said she liked the even proportions of historic architecture, making it comfortable to look at despite its extensive architectural detail. This was borne out recently when, as I have already mentioned, KM moved briefly to a historic town, finding she could function in its high street, which she cannot do in her hometown.

KM says she can process predictable architecture as exemplified in the picture of Somerset House and the random shapes found in nature. What she cannot process are designed shapes that are neither random nor predictable. This is illustrated in the example she gave me of a relatively recently designed street in figure 31.

Figure 31. A ‘designed’ street that KM is uncomfortable looking at. Photo: Google Maps

However, the street in figure 32 below which has developed organically over several hundred years she says is easy to process possibly because it has a more consistent pattern within each building.

Figure 32. A street that has organically developed over time which KM describes as being equivalent to Tellytubbyland. Photo: Google Maps

Compensatory spatial strategies

KM says she needs some spatial cues to process her environment, if there are too many she becomes overwhelmed, if there are too few then she cannot analyse the space. Spaces that are easy to process include McDonald's restaurants, which KM seeks out when travelling, as the layout, menu, and staff uniforms are always nearly the same. KM says this allows her to generalise information from one restaurant to another without having to reprocess the space. KM says that Macdonald's like Teletubbyland uses simple shapes, colours and layouts which are easy to process as illustrated in figure 33 below:

Figure 33. Example interior of a traditional McDonald's restaurant. Photo: lkuzyk

During our discussion, I found a picture of a new style MacDonald's which I thought would be more difficult and uncomfortable to process due to the introduction of curved armchairs, illustrated in figure 34 below:

Figure 34. Interior of the modern McDonald's. Photo: coolboom.net

When I e-mailed the photograph to KM she said saw the backs and seats of the chairs as one shape, memorising them as ‘s’ shapes.

Figure 35. Curved chairs recently added to the interiors of British McDonald's restaurants. Photo: www.bonluxat.com

During our discussion I pointed out the round stools to KM, she said if I had not told her the circles were stools she would have seen them as part of the pattern on the floor. This illustrates KM’s lack of intuitive perception of the difference between two

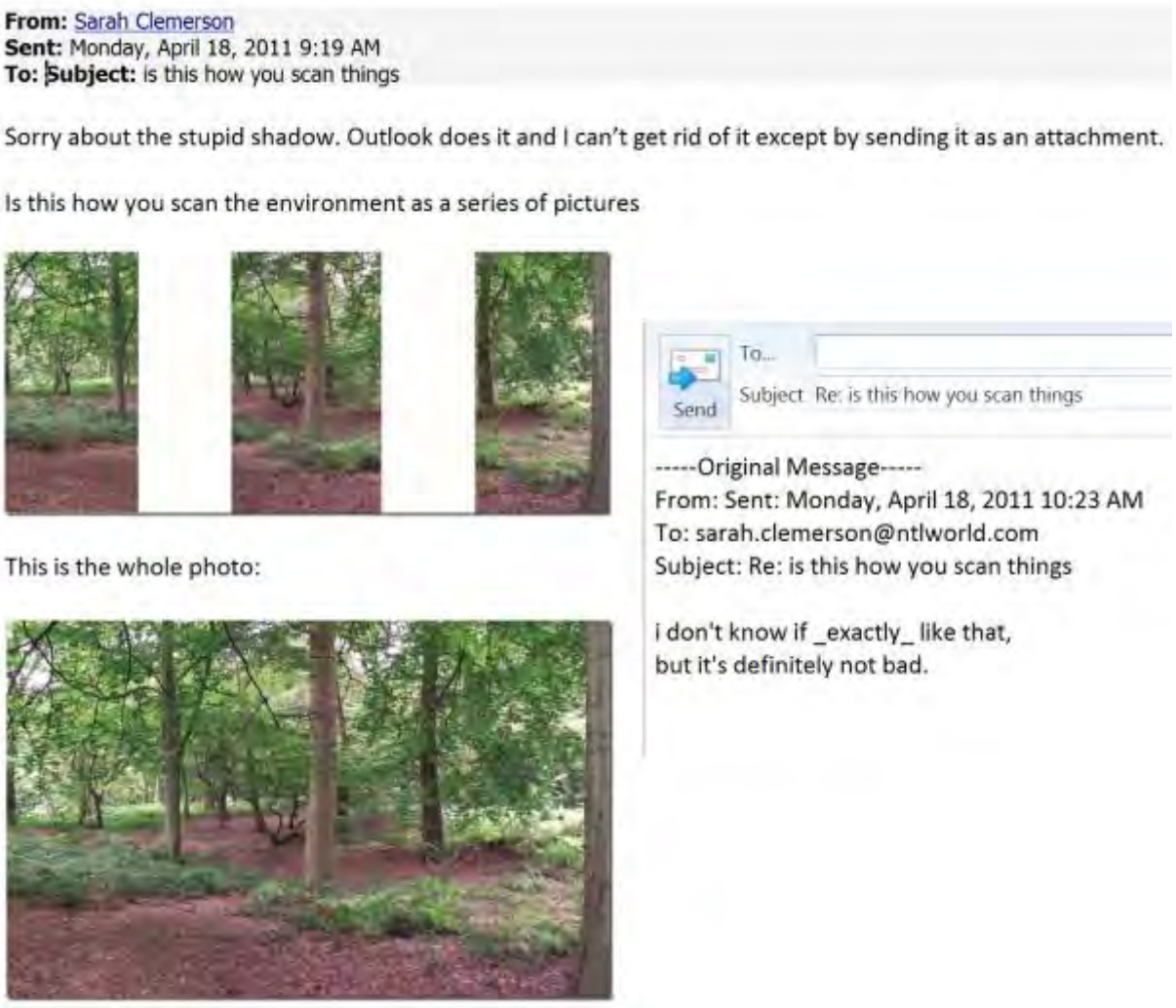
and three D space, possibly exacerbated by the flattening effect of the photo. When we discussed this KM said she knew three D space existed logically (Ben Shalom's level 3) but could not feel it (level 2) (Ben Shalom, 2005:643). This is similar to Gerland's experience as a child, her vision being flat like a photograph (Gerland, 1997:65f).[17]

What KM sees

My stay at KM's home, which will be discussed in detail later, highlighted the effect of her visual perception on her use of space. This provoked intense e-mail and telephone discussion and demonstrated our negotiation of the hyphen to understand perceptual difference. I attempted to visualise what KM sees by manipulating photos using image-editing software. The following presents the dialogue; demonstrating how the participants and I worked to clarify our understanding of the data. I will allow the e-mails to tell the story, adding explanation where needed for clarification.

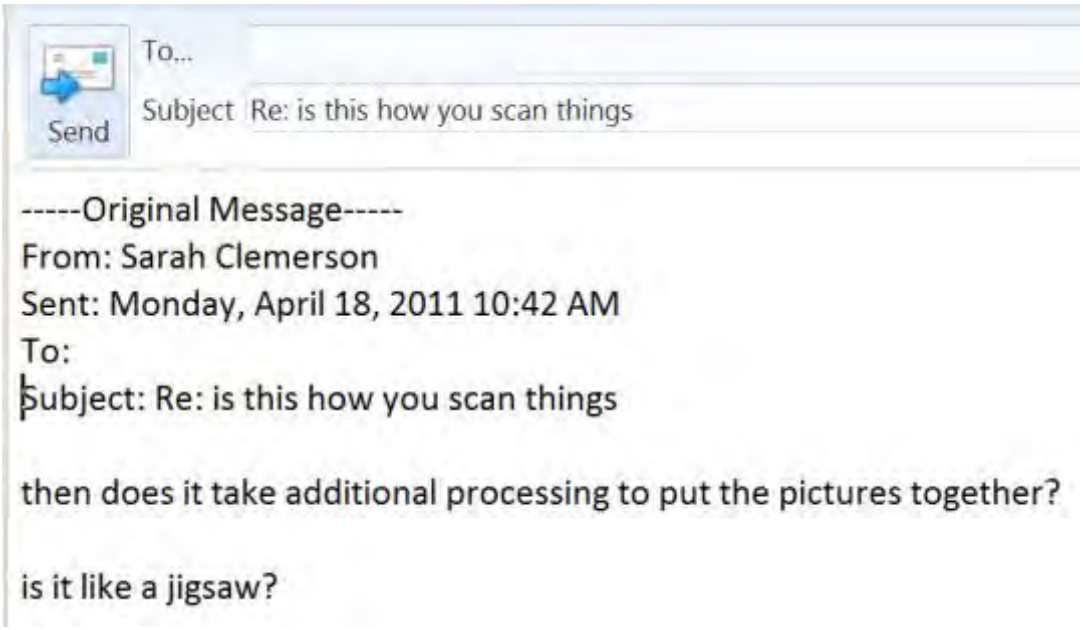
[17] Further discussion of stereoscopic vision and other visual differences can be found in Sacks book the Mind's eye (Sacks 2010).

From Sarah:

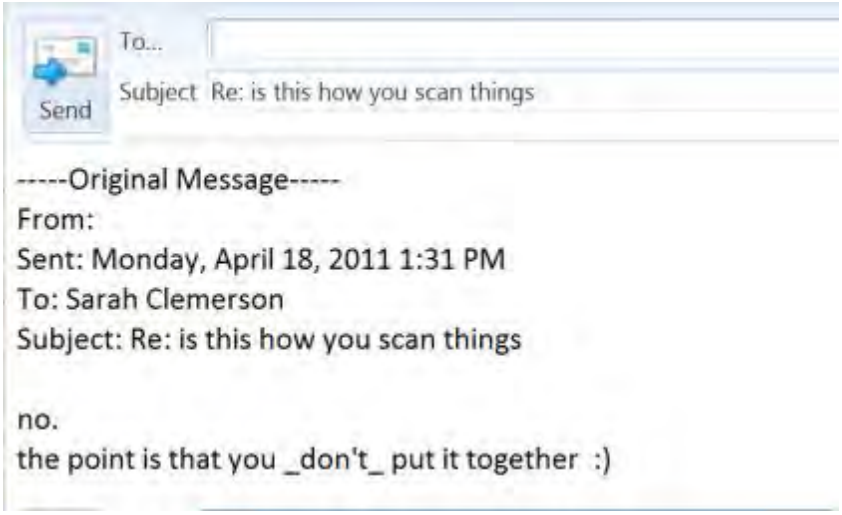


When I was staying with KM, she described having to scan her environment to find people; for instance, restaurant staff. This prompted me to attempt to replicate what she might see during scanning. Firstly, shadow along the bottom of the top photograph, which appears insignificant, creates yet another object for KM to process. An example of one of KM's compensations for this is leaving the original packaging on the bottom of her fridge, to avoid having to process the shadow caused by the gap between the fridge and the floor. This seems a minor issue, however details like this add hugely to KM's processing.

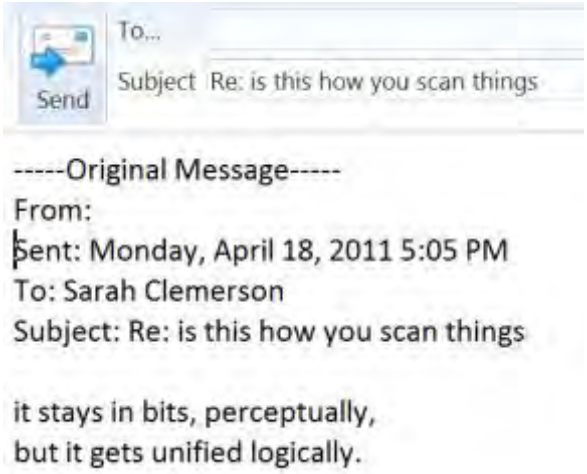
From Sarah:



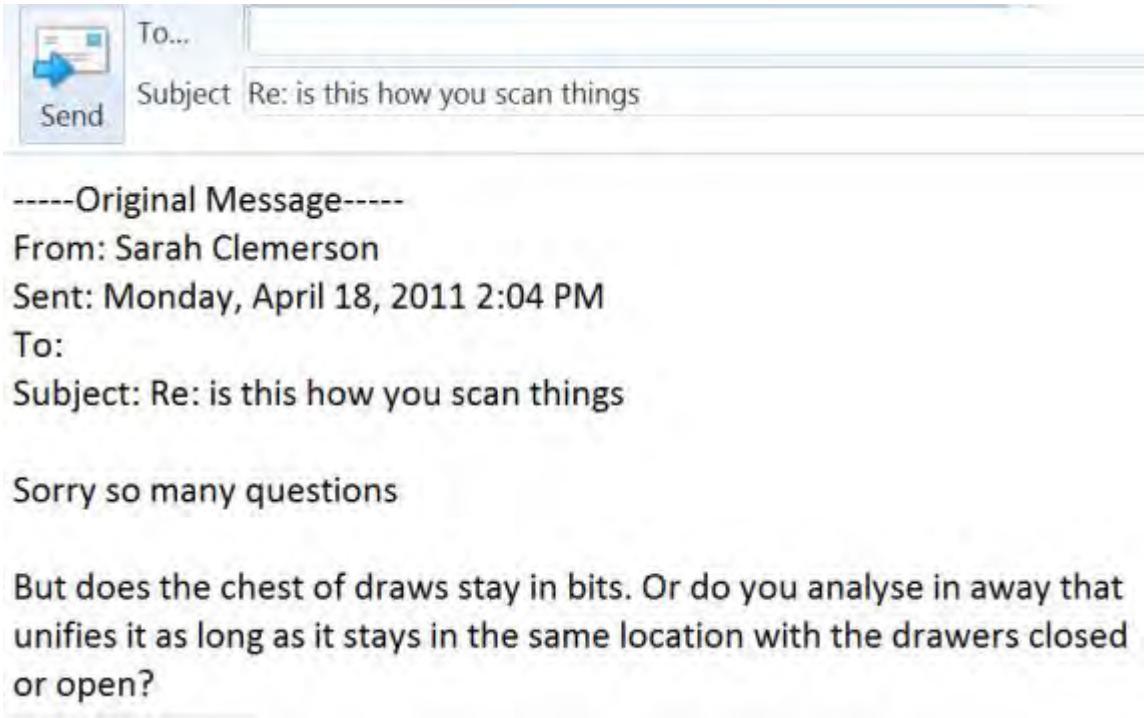
From KM:



From KM:



From Sarah:



I found the phrase 'stays in bits, perceptually, but then gets unified logically' incredibly complex. I would think I had understood and then understanding would slip away again. The danger is now I think I fully understand what KM is saying it could obscure how difficult it was initially to comprehend her perceptual experience and

therefore to explain it clearly to others. I also put the rider 'think' in because I believe autistic and typically developing people's experience, relationships and dialogue are not static, needing development through on-going negotiation of difference to understand and find words for our experiences. The example presented here was one of a number of moments during this study when I could not understand what I was being told. It was not until presenting Ben Shalom's integrative theory of autism at the Wales 4th International Autism Conference, in her absence, that I understood what KM meant (Ben Shalom, 2011b; Ben Shalom and Clemerson, 2011). Until then I had not grasped the implication of KM's scanning of space at level one, the level of a baby or very young child, whose vision is not yet unified (Hamer and Mirabella, 1990).

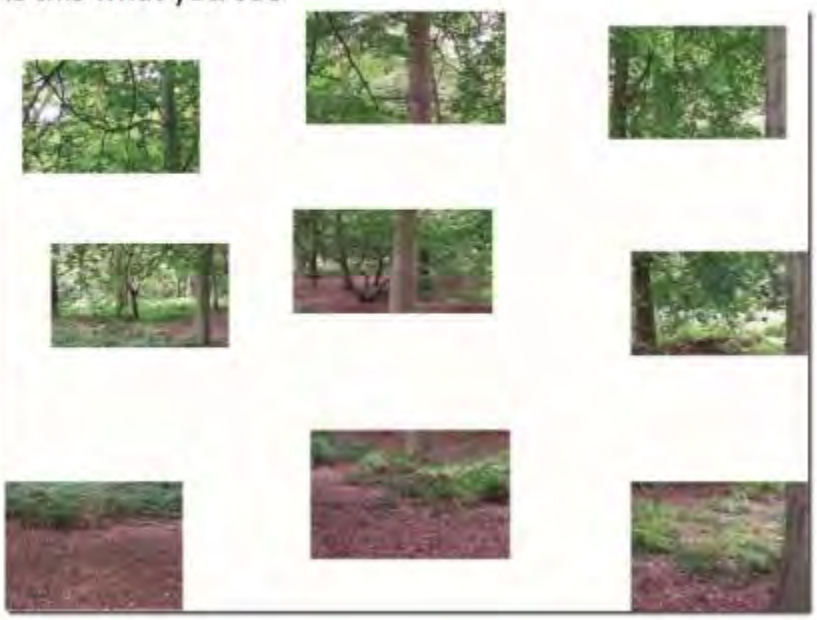
KM describes scanning as similar to taking a series of still photographs, explaining why she cannot visually locate restaurant staff or taxis, as they move before she can unify her vision to find them. This is complicated as KM says she cannot move her eyes properly, which means she also 'cannot do joint attention', as she cannot track others' gaze fast enough. Part of this is because she relies largely on peripheral vision. This gets her into trouble with conductors when she is singing because it appears she is not reading the music. Ben Shalom suggests there is a failure to integrate information received by the fovea, at level 2 of her integratory theory. This leads to the fovea being overactive and ineffective, causing so much discomfort that peripheral vision is preferred as it is less distorted (Ben Shalom, 2011d).

To return to the emails our dialogue continued:

From Sarah:

From: Sarah Clemerson
Sent: Tuesday, April 19, 2011 7:54 AM
To:
Subject: trying to see what you see

is this what you see



or is it more distorted.

From Sarah:

From KM:

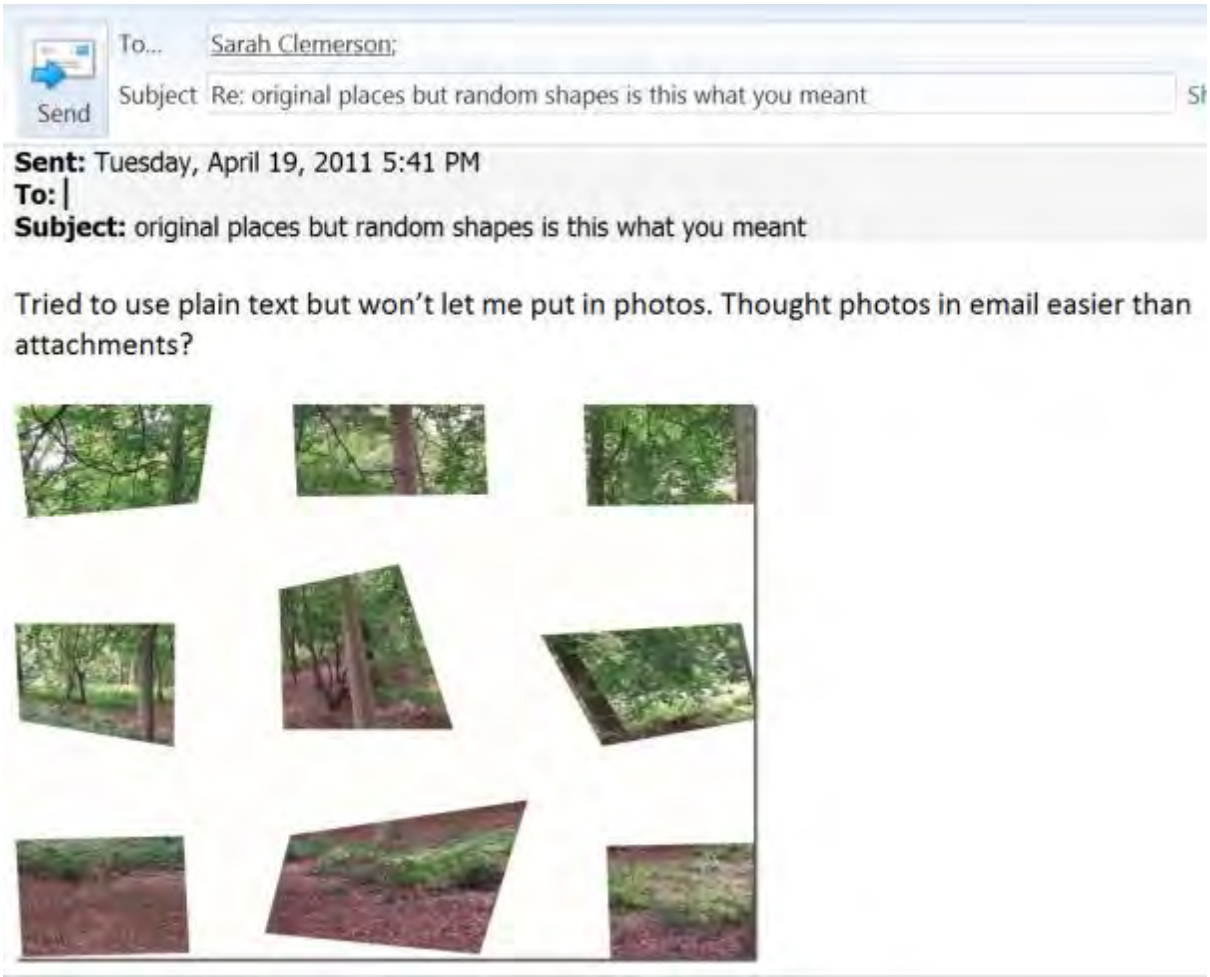
-----Original Message-----
From: Sent: Tuesday, April 19, 2011 11:11 AM
To: sarah.clemerson@ntlworld.com
Subject: Re: trying to see what you see

like the random picture,
but with the different bits in random (regular) places.

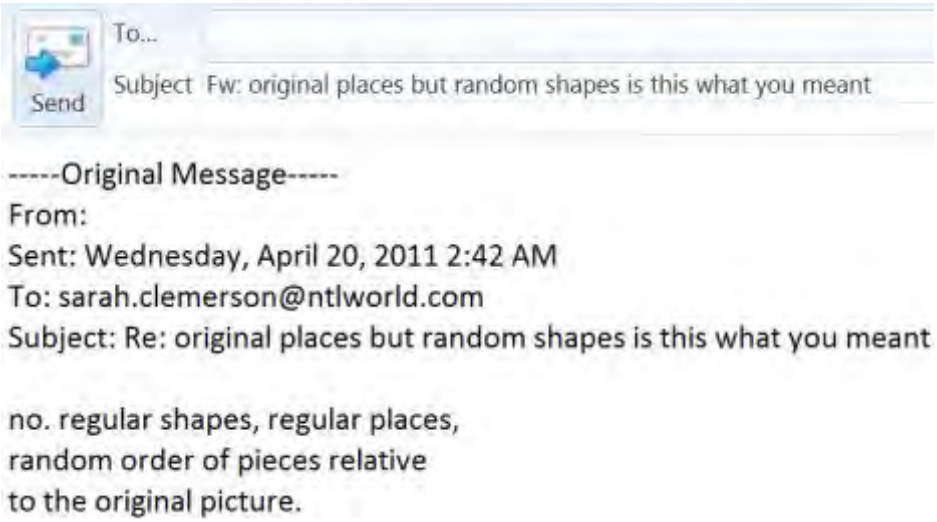
does this make any sense ?

When I began this study, I associated visual fragmentation with visions of irregular, shard shaped fragments. However, in KM's case I was wrong. What she was seeing as we will see further on, were regular squares, placed in an orderly fashion but in the wrong order, as we will see below:

From Sarah:

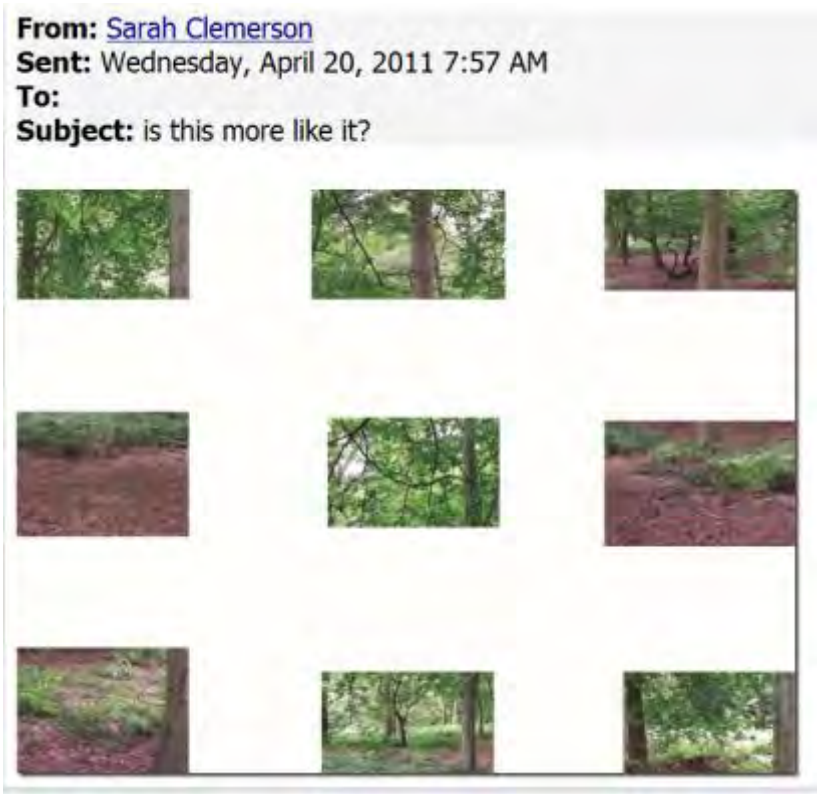


From KM:



I then produced this:

From Sarah:



Not satisfied with that photo I wanted to see what KM might see when walking down the street resulting in the picture in figure 36:

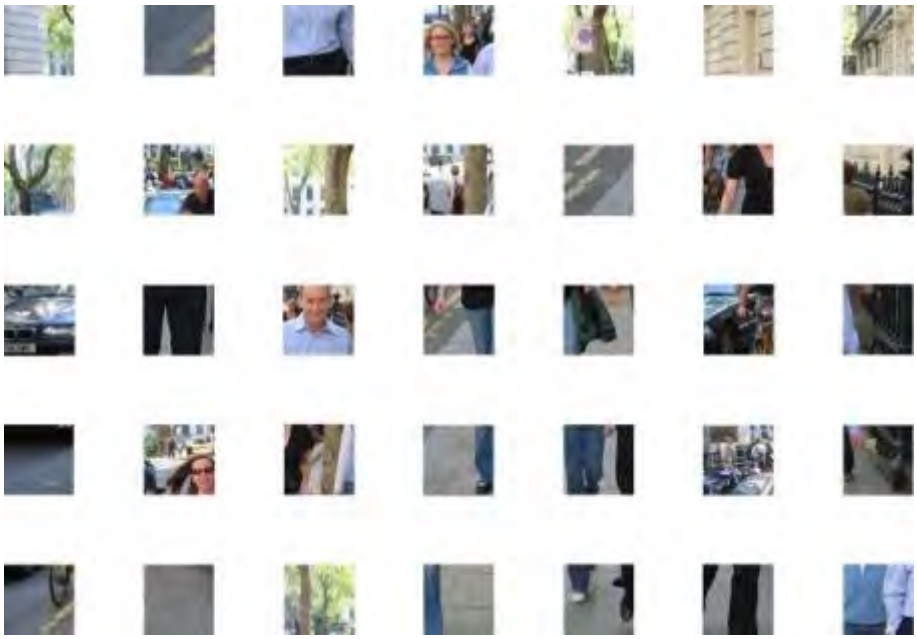


Figure 36. Final image produced as a result of the above e-mail and telephone exchanges

And this was KM's comment:

-----Original Message-----
From:
Sent: Friday, April 22, 2011 2:28 PM
To: sarah.clemerson@ntlworld.com
Subject: Re: is this more like it?

yes.
this is very good.

many many thanks !

The original picture looked like this:

Figure 37. Photo before manipulation. Photo: http://www.krisrzepkowski.com

It is easy to see from the emails and figures 36 and 37, how difficult it is for KM to quickly comprehend and respond to what she sees. This is complicated by the absence of intuitive, preconscious motor planning, reading of motor action, and episodic memory. Episodic memory is used to store memories of previous events/visits to a location to assist wayfinding. This will be discussed later on during my description of a journey undertaken with KM and my stay in her home. Continually having to piece the environment together means KM quickly becomes exhausted by space. She compensates by rationing her activities and using semantic memory, which relies on logic at level 3 (Ben Shalom, 2009:589f). Elovic, also describes using semantic memory to compensate for her disunified vision, teaching herself to see using memory and other systems (Elovic, 2008).

However, KM can find objects spontaneously in her environment, such as when we were walking and she spotted a bird and some detailing on a building. What she says she has difficulty in doing is spotting objects, which are pointed out to her due, as I have already mentioned, to not being able to turn her eyes.

Faces

KM experiences similar visual disunification in relation to faces, resulting in difficulty recognising people. KM says she compensates for this by memorising how different people move. In autism difficulty, recognising faces is thought to result from social ‘impairments’. However, Behrmann et al’s review corresponds with KM's experience, arguing that issues with facial recognition may be due to visual, perceptual difference rather than entirely social ones (Behrmann et al., 2006:258). Along similar lines Scherf et al suggest, that the functional topography of the face-related cortex is selectively disrupted in autism which accounts for difficulty in facial processing (Scherf et al., 2010:2).

The following discussion between KM and I also carried out via e-mail and telephone illustrates her facial perception, using the photograph in figure 38 below:

Figure 38. Original photo before manipulation: Photo: Ruckas Pictures

In figure 39 below is my first attempt at fragmenting the photograph:

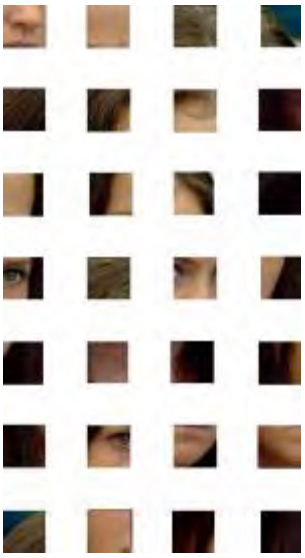


Figure 39. Photo after fragmentation

KM's response to this:

To: Sarah Clemerson;

i fragment the face, not the eyes,
and it is to larger bits than your fragmentation.

Figure 40 shows the photograph manipulated according to KM's comments:

Figure 40. Photograph manipulated according to KM's comments

Eye contact

I chose the photograph because of the troubled eyes. Eye contact is an important expectation of interactional space, to instigate and negotiate communication. KM

says that eyes that have a question or emotion in them are very painful for her to look at. Below in figure 41 is a diagram of how this might be:

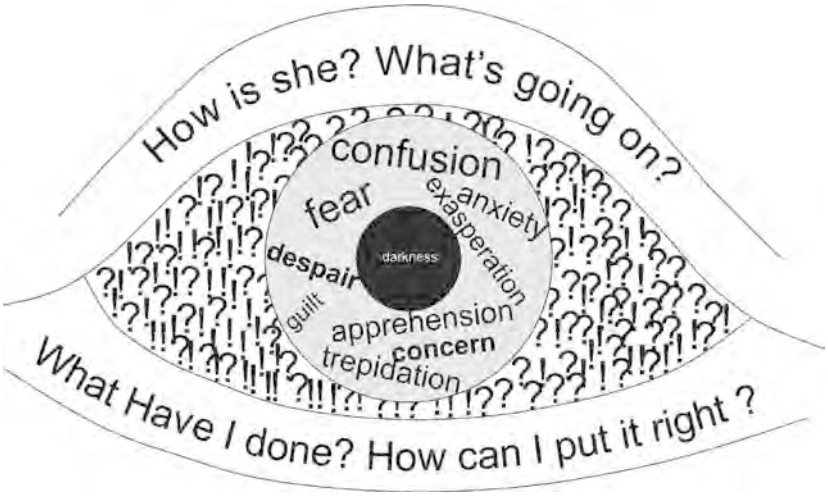


Figure 41. Eye filled with emotional content

KM expressed exasperation with the social requirement for eye contact, during the journey described in the next section, arguing that humans are one of the few animal species that require this. However, she says a passing gaze, such as when making conversation is not uncomfortable, as it has no question or emotional content as illustrated in figure 42.

Figure 42. An eye with little emotional content as when engaged in unselfconsciously talking

This affects KM's functioning in social and interactional space; expressing her sense of injustice and affront at the blanket assumption that autistics cannot read social cues. KM argues that she would be able to read them if she could unify her vision fast enough to respond to their content. Smith also says the eyes are the worst parts of the face for him, as they give off more information than the other parts (Smith, 2006a).

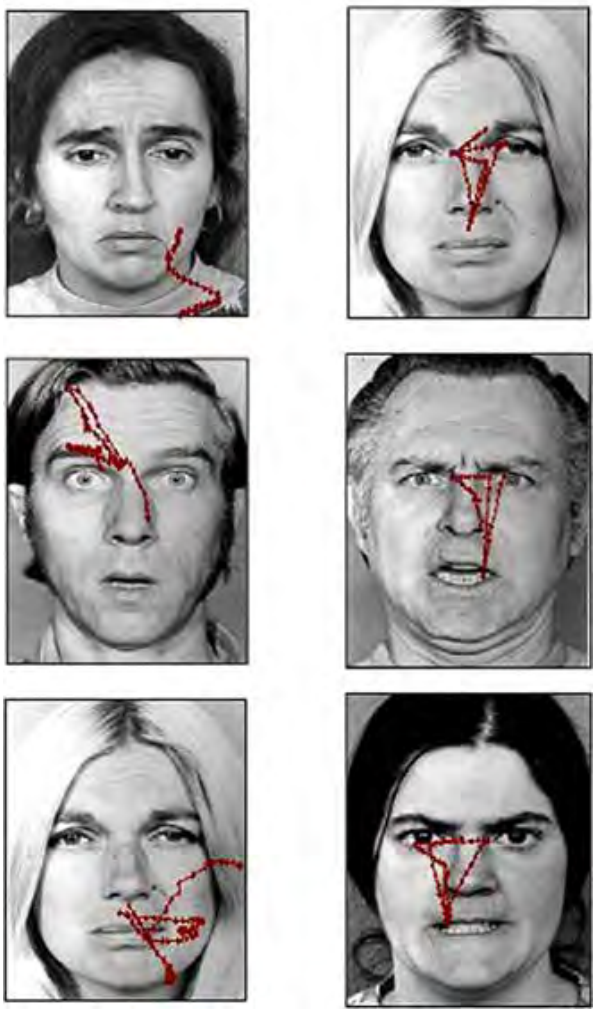


Figure 43. Illustrating how autistic people focus on other regions of the face rather than the eyes. Source: (Pelphrey and Carter, 2008:292)

Pelphrey and Carter, in their research showed photos of people exhibiting extreme emotions, to autistic and typically developing people, illustrated in figure 43. They found, using eye tracking, that autistics looked randomly at the faces, rather than focusing on the eyes. Pelphrey and Carter assumed this suggested a failure to examine facial features to pick up social cues (Pelphrey and Carter, 2008:292). I suggest it confirms KM and Smith's accounts of their avoidance of eye contact, and that the findings of Dalton et al's MRI study present a more accurate explanation.

Dalton et al found that eye fixation is associated with hyperactivation in the central circuitry of emotion, producing heightened sensitivity to social stimuli, making eye contact uncomfortable for many autistics (Dalton et al., 2005:524). Others have made similar observations, Senju and Johnson quote Kylliäinen and Hietanen, who found that autistics showed heightened arousal to direct gaze (Senju and Johnson, 2009:1210).

This process depends on the use of visual frequencies, which Senju and Johnson argue are affected by atypical specialization of the social brain and the subcortical face and eye contact detection route. This in turn creates atypical communication with the cortical and subcortical social brain network (Senju and Johnson, 2009:1211). The photographs in figure 44 demonstrate the use of vision frequencies by typically developing people. The left picture shows high level, spatial, visual frequencies, which depict edges and fine detail. The right picture shows low-level spatial frequencies which represent global information regarding the proportion and position of objects (Bar, 2004:621). The middle photograph shows the integration of both speeds of frequency.

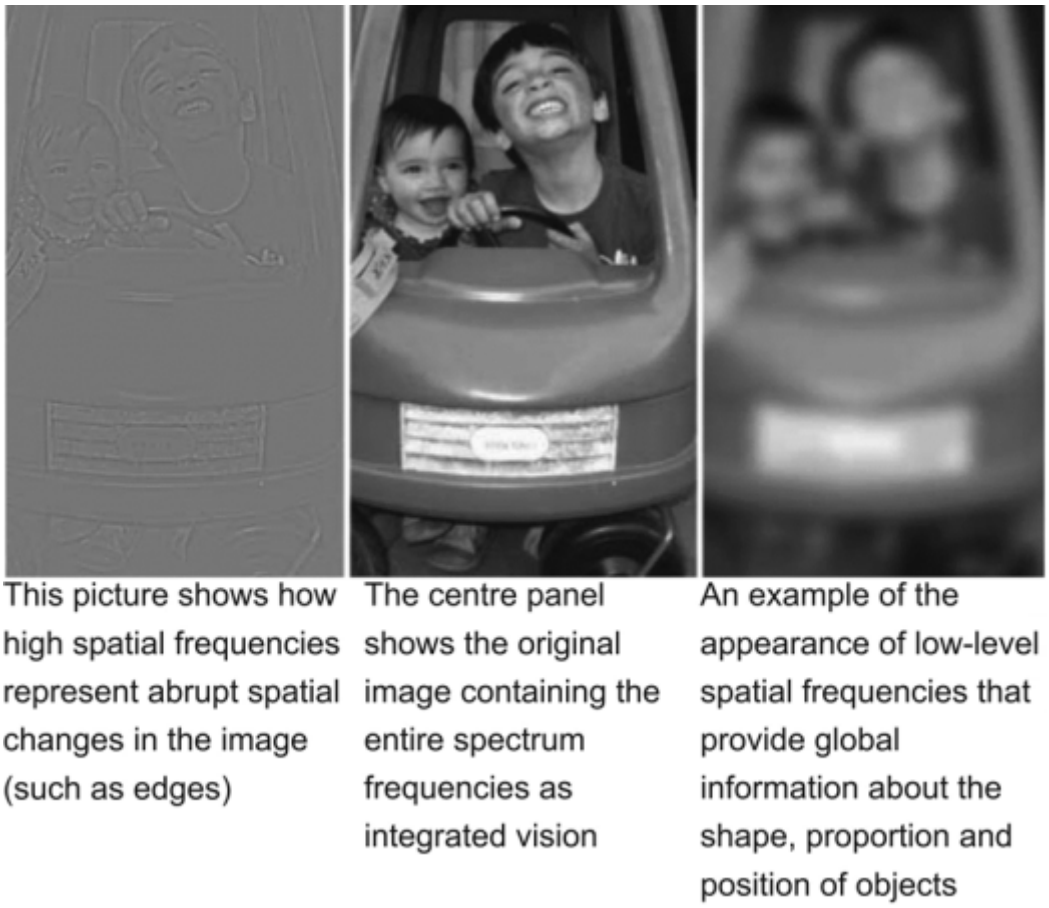


Figure 44. Photos showing how different spatial frequencies convey different information about the appearance of a stimulus. Source: Bar, 2004:621

Ashwin et al argue that faces are made up of distinct features of high-spatial frequency that require integration at global level to extract all the information (Ashwin et al., 2009:20). To suggest why this is impaired in autism they refer to event-related, potential and functional magnetic resonance imaging studies which show that low-level spatial frequency is more effective than high spatial frequency for facial processing (Ashwin et al., 2009:20). Ashwin et al go on to suggest that as autistics have atypically high spatial-frequency abilities, they may not be able to 'overcome' this ability to process global information. This means they do not use low and other frequencies to rapidly extract and integrate information from faces, bodies,

demeanour or indeed the central concern of this thesis, spatial elements (Ashwin et al., 2009:20; Bar, 2004:621).

Night vision

However, one aspect of vision KM excels at is night vision, because as I said in chapter 3, her peripheral vision is more unified than her central vision. This is because the periphery of the retina mostly consists of rods, which as I indicated in chapter 3, are used to see in poor light (Crick and Khaw, 2003:264). KM illustrated the effectiveness of her night vision to me many times, the most notable being when we visited a friend's house. I could hardly make out the house, never mind navigate the steep steps down to the basement, but KM did so with ease, possibly assisted by her excellent procedural memory, discussed in Chapter 4, Section 2.

Virtual space

Virtual space is crucial to KM, being her work, social and leisure space. Like Davidson I argue that virtual space is a space in its own right, with its own ideological, contextual and interactional elements, that largely rely on written programmes (Davidson, 2008:791). This makes the Internet highly accessible to autistics such as KM, who relies on logic and semantics and is easily sensorially overloaded by space and social interaction. Many autistics say it is a powerful tool, the equivalent of sign language for the deaf (CBC Canada, 2008; Dekker, 2005). This is because written discourse is easier for many autistics to process and respond to, whereas speaking and processing others' speech, body language, tone of voice, pace of speech, social and spatial demeanours, and mirroring them requires integration Ben Shalom's level 2. Gerland illustrates this difficulty, saying smiles on their own are enough to confuse her (quoted in Davidson, 2008:795). In addition, in

virtual space, the speaker can choose when to respond, instead of having to answer immediately as required in physical space. This slows discourse, masking difficulties in comprehension, that stereotype the individual as socially inept (Davidson, 2008:796). Virtual space also hides any unusual demeanours, which if visible, may cause people to dismiss autistics' views (Murray and Aspinall, 2006:7).

KM's processing of virtual space

Despite KM's preference for virtual space, she processes webpages and computer interfaces in the same way as physical objects and spaces. She says she processes the most popularly used fonts by memorising them using semantics, so that she can read other's documents (Ben Shalom, 2009:589f). However, what she often cannot process are the icons that we all take for granted as illustrated in figure 45 below:

Figure 45. The tool bar from Word 2010 showing the immense number of curves to be processed

The immense number of curves in each icon makes this and similar applications painful and exhausting for KM. KM demonstrated how she works from the kernel of the system on her small laptop. The kernel provides a bridge between applications and data processing hardware. KM uses Red Hat LINUX 9 as an alternative to Microsoft applications. Using this application, she creates her own scripts to operate her personal computer. This involves logic, semantics, perceptual and verbal

working memory, allowing KM to compensate for issues with motor planning. She says scripts are predictable whereas pre-set defaults in applications such as Microsoft Word are not.

KM has simplified her laptop screen so that she can instantly find everything as she says she cannot search for it. Even though the screen is tiny, it has four panes on its screen, programmed to open in the same place, at the same size, each time she opens her computer. She has also programmed it to open with an empty screen to allow her vision to settle before the other applications open.

KM said she preferred the early cathode ray monitors as the text was in columns. With new monitors the text is centred which is harder for her to read. She says that when she works on her own documents she can only use one size and style of font, as she cannot generalise one font size to another. This means fonts of different sizes have to be processed from scratch as they look like another type of font. Red Hat LINUX 9 has a uniform font of white letters and black background; all the text is in columns, justified to the left. KM says she can only use this version to produce documents and when communicating with others using a computer. Although support for Red Hat LINUX 9 is discontinued, KM says she cannot use the newer versions of LINUX as they have red and green letters that are too difficult for her to process.

Section 2: Narrative and analysis of a journey I undertook with KM

In this section, narrative of the go-along is written directly on the page, the participants', and my commentary and analysis is in the grey boxes.

The narrative shows clearly how I made inaccurate assumptions when sharing space with KM. Within the grey boxes I explain how, based on her demeanour and spatial functioning, assumptions were made. This is then triangulated with autistic authored and academic writing.

Through narrating the story of KM and my journey, which formed an extended go-along, I hope to draw the reader into our experiences so they can see the process by which alienation developed between KM and I. This develops some of the issues that caused confusion to the woman attempting to give directions to CD and the solicitor, in the club, who tried to tell EF he had toilet paper stuck to his shoe. In this case though, the effect our demeanours had on each other had more extreme effects on our spatial comfort, over several days rather than hours.

When I started to share my narration of the journey, I was concerned it would upset KM. We live too far apart to have live discussions, so with trepidation I shared what I had written over the phone to gauge her reaction. KM however, was matter of fact about what had happened. She feels as I do that our emotional responses to and perceptions of each other's demeanour during the journey provide important data. In this instance, they illustrate how misunderstandings may develop between autistic and typically developing people and how they affect the spatial comfort of both. This was a key moment in the research process, which gave me confidence and intensified KM and my discussion which continues to date. On my part, I maintained an awareness of Fine's concept of the hyphen and Jones and Jenkins's application of it. This to some degree maintained my awareness of the possible differences

between KM and my spatial experience, our expectations of each other and assumptions made when they were not met during the journey (Fine, 1998; Jones and Jenkins, 2008). Of particular importance was my initial ‘othering’ of KM, which took me by surprise and my struggle to maintain an equal relationship with her.

The journey

The journey took place overseas, involving a two-day trip by train, an overnight stay in a hotel, 24 hours on a coach and a two-night stay in another hotel. The journey’s episodes are narrated chronologically by me. The analysis and findings in this section focus to a greater extent on the ideological and interactional elements of space, which were exacerbated by the physical and sensory context of the journey.

The waiting room

KM and I meet at the train station, where we bought food for the journey, before going to the waiting room, similar to the one in figure 46:

Figure 46. Example of a similar station waiting room, to the one we experienced. Photo: moynihanstation

It was large, noisy, and full of reflections from fluorescent lighting, threatening to overwhelm KM. She said she would have liked a quieter place with no fluorescent light, but when I suggested going onto the platform she declined.

Autistics' issues with fluorescent lights and noise are well documented. Holliday Willey says light on its own is enough to cause overload and Williams that it makes her go to sleep (Holliday Willey, 1999:26; Williams, 1992:126,158). I will fully discuss KM's views on fluorescent light and her strategies to deal with it in the next section, where I discuss my stay in her home.

The inflexible application of social rules

KM only had a backpack, to reduce the energy needed for motor planning. She was very concerned that my bags were in peoples' way. I felt somewhat disgruntled, suggesting that we move to somewhere where there was more room. I was disgruntled because everyone had their bags in the aisles, moving them when people needed to pass. I was puzzled why KM did not see this[18]. A similar thing had happened in MacDonald's when we were buying our food; KM insisting we move to one side when she had ordered her food, as 'in this country you have to keep out of peoples' way'. In both situations, I was a bit 'put out' and felt 'told off'; puzzled and somewhat defensive, having a passing feeling of 'who are you to tell me what to do'. Subsequently I thought it might just be KM's manner. In the event 'keeping out of the way' meant the server could not see KM to give her meal.

The two examples above show how it helped not to be an 'autism expert'. As such, I could have dismissed KM's functioning in this episode as 'autistic behaviour' without reflecting on how irritated I felt and how this affected my spatial comfort. The effect was that instead of zoning out or catching up with KM's news and our trip, I was stressed by her insistence to 'keep out of the way' and her concern about my bags; feeling my behaviour in response to those around me was my responsibility not hers.

When we discussed this later, KM said that she has an acute social awareness, memorising social rules using logic, rather than instinctively applying them (Ben Shalom, 2009:589). Zalla et al found in their study, that contradictorily autistics did

[18] We had not yet discussed KM's vision

not comprehend the emotional impact of a faux pas whilst being aware of the violation of social rules, which corresponds with KM's assertion. Zalla et al also suggest autistics may over learn social rules (Zalla et al., 2009:373). Applying Ben Shalom's levels of functioning, I would suggest that this is not due to over learning but due to the use of logic at level 3 as a compensatory strategy due to impaired preconscious integration at level 2. As I argue in my analytical framework, rules created by logic are not flexible enough to deal with the nuances of rapidly changing interactional and contextual elements of space. KM can respond instinctively to the emotional states of others, but cannot integrate the information from levels 1 and 3, at level 2. Most of the typically developing population do this preconsciously and effortlessly at level 2, across all four of Ben Shalom's domains, to produce the required social demeanour (Ben Shalom and Clemerson, 2011).

This example illustrates the partial accuracy of rules developed using logic; socially you should not inconvenience people by getting in their way. However, rules developed using logic are not flexible enough to meet the ideological and contextual demands of social and interactional space. In this case, the waiting room where the gaps between the rows of seats were not big enough to accommodate luggage and the passage of people, meaning people could not help but 'get in peoples' way', compensating by moving their bags every time someone wanted to pass. In a similar manner it was socially acceptable for KM to wait at the counter, so the server could see her to give her food her. However, whilst doing this KM would have had to read the preconscious motor actions of others, and make her own motor actions readable to negotiate the space in front of counter. The social expectation is that while KM waits she makes sure she can see the server and the server can see her, so when

her food is ready, it is handed over without confusion.

The development of unintentional double-binds

I suggest these give an example of how autistic demeanour comes to be stereotyped as inflexible and how this irritates those around them, causing spatial tension. The autistic person's rules are partly right, in this case ‘not to get in peoples’ way’, but in a crowded McDonald's or waiting room this is impossible, creating what Bateson describes as a double bind. He used it to describe the effects of some parents’ interactions on their adult children with schizophrenia (Bateson et al., 1956:253). The double bind is complicated by typically developing people not easily being able to verbalise the nuances of preconscious, unwritten interactional, emotional, and spatial expectations. Therefore, it is difficult to explain that it is all right to 'get in peoples’ way’ in this certain circumstances; complicated by autistics often being hyperaroused. This does not allow typically developing people to explain their point of view, leaving them feeling impotent.

Later when I discovered, as I have outlined in the previous section that KM scans space as a series of pictures which she then unifies, she also told me she cannot 'zoom in'. This means she cannot process her vision fast enough to continuously assess social and spatial cues from others’ behaviour. Something typically developing people do preconsciously.

Why understanding the effects of this episode on space is important

The server in Macdonald’s may have resented KM's demeanour as it interrupted her workflow, a major ideological element of a fast food restaurant, causing confusion,

threatening the server’s competence. This could have caused a fractious exchange, heightened by KM being overwhelmed by the necessity to simultaneously process the interactional, contextual, sensory, and motor elements of space to produce the expected demeanours.

The examples of the queue in McDonald's and the crowded waiting room illustrate how apparently simple, straightforward situations can affect the spatial comfort of those sharing space with autistics. KM's demeanour did not match my social expectations. As a result, the space became tense and some of KM's heightened arousal transferred to me. I felt imposed upon by her arousal, when I wanted to relax, showing how easily resentment leading to spatial tension develops from minor incidents. This is complicated when there is an assumed hierarchy, for instance when a support worker accompanies an autistic person. As a support worker, I have experienced similar incidents that challenge the authority of the worker on preconscious and conscious levels often leading to defensiveness, without fully understanding how or why this occurs. I genuinely wanted an equal relationship with KM and resented the feeling that she was attempting to control me.

It is important to understand this; I have witnessed the effects of long-term resentments, for instance, support workers feeling deskilled because of behaviour they felt was an appropriate, leading to mythmaking, perpetuated long after, even many years. These emerge from the challenge their demeanour presents to those in authority and can lead to the objectification of autistics and other people. This objectification perpetuates with social impairment inaccurate assumptions and expectations, leading to spatial tension, often impacting on spatial functioning and

access to travel, employment, education, leisure activities and appropriate support services as we will see in chapter 5. This may lead to social space becoming a battle of wills between community, family, and/or support workers leaving the autistic person bewildered, as we will see in the case of MN in Chapter 5.

In McDonald's and the waiting room, what KM said made perfect sense to her, a statement of fact to control my behaviour in the moment, so we could comply with her rule 'not to get in peoples' way'. However, the powerful emotional effect of these episodes was that KM was attempting to control my entire life, which was irrational. In addition, I felt criticised, casting doubt on my acceptance, and competence within my professional and social reference groups (Shibutani, 1955). All this, when all KM and other autistics wish to do is control the behaviour of those sharing space with them, in a specific moment for a specific purpose without placing extra demands on their processing. This study shows many autistics do not have the interest or processing power to manage any other aspects of the lives of those around them. Furthermore, it emphasises the central role of the emotional impact of differences in some autistic demeanours on the spatial comfort of those around them. This study illustrates these often-erroneous assumptions, which result in the drip of social exclusion demonstrated by the cases of CD and EF, and the extreme consequences of alienation and homelessness described in Chapter 5.

Getting the train tickets – a preference for machines over people

Once we had our food, we went to exchange our voucher for a train ticket. I automatically assumed we would queue for this, however KM headed to the nearest ticket machine. I was doubtful we would successfully get our tickets from it, as they were booked overseas. However, despite distraction from fluorescent lighting and

the commotion of people, KM quickly navigated through various screens and got them. I discovered this is an important strategy used by KM to save the processing power needed to interact with a person. KM said machines are easy to process, as they only require logic and semantic processing; making the outcome more predictable than talking to a person.

Personal interaction requires preconscious processing at level 2 in all four of Ben Shalom's domains. KM only uses level I, which is a reactive, unconscious level relying on habit and skill and level 3, which employs logic. This bypasses the integrative function of level 2 (Ben Shalom, 2009:589). This means that if KM buys tickets from a person she has to consciously process all her interactions with them, a largely preconscious process in typically developing people. Firstly, she would have to integrate her vision and motor planning to find the ticket counter, queue, and the ticket clerk at the head of it. Then KM would have to consciously process all the physiological, cultural, and other tasks to present the correct tone of voice, language, mannerisms, and so on to interact with the clerk. This requires KM to consciously assess the emotional state and competence of the ticket clerk, adjusting her demeanour to theirs, creating the short, reciprocal relationship, to allow her to buy the correct ticket with minimum confusion.

KM's processing effort would not end here; she has to remember which ticket she needs. This is complicated by her lack of episodic memory; meaning she cannot visualise routes or tickets of past journeys to inform her current purchase. Therefore, it is not surprising that KM uses machines to avoid the 'many unpredictable variables' of personal interaction, which exacerbate her hyperarousal. Kirshenbaum

et al argue that hyperarousal negatively impacts on episodic memory (Kirschbaum et al., 1996:1475). Figures 47 and 48 below illustrate the many elements to be processed when buying tickets from a person versus a machine.

Figure 47. Aspects of buying a ticket from a person rather than a machine.Photo: http://www.hstimpactstudy.net

Figure 48. Illustrating the advantages of a ticket machine for KM. Photo: http://www.tradekorea.com

On the train – alienation from KM

During the journey, KM was very quiet, avoiding eye and other personal contact. At first, I did not worry too much about this; I often like to lose myself in my own thoughts, the scenery or read on train journeys. The carriages[19] were shabby but not that noisy or overcrowded. It was not that comfortable but I was used to it and KM is also a regular traveller. After about twelve hours with no communication from KM, I became more uncomfortable. I sensed KM was not happy and wanted to find out what was wrong or if there was anything, I could do. However, KM's demeanour told me she wanted to be left alone. Despite this, I was compelled by the wish that she would speak to me so I knew 'where I stood'. By this stage, even acrimonious conversation would have been reassuring. Without it, I felt tense and in limbo, which increased as time went on, KM's body language seeming to exude hostility, and what was worse, disapproval. Instead her blank, but rigid body language completely shut me out, the train carriage turned into a dark, desolate, and hostile space. I felt completely isolated. Previously, I had spoken many times and at length with KM on the phone, where she had been until this journey, lively and engaging, now she was bunched up with what I perceived as defensiveness and hostility. If the journey was badly affecting her senses I felt she could have told me, at least I would have known what was happening, even if I could not have done anything about it.

[19] Rail carriage or passenger car

Figure 49. Example of the train interior that became a dark, desolate, and hostile space. Photo: James-Quinn

I felt a sense of injustice, KM would not tell me what was wrong or what I had done, so I could not put it right or attempt to make her feel more comfortable. Again, I felt caught in a double bind. I was supposed, socially and professionally to be able to help, but was being rejected, KM sitting away from me most of the time on the train. I tried to take my mind off what was happening, but anytime KM was in my eye line, I could sense her misery.

I felt extremely stressed, I felt I was a terrible person. It was natural that I should be apprehensive on a long journey in an unfamiliar environment, but not this crushing feeling of doom, frustration, a sense of everything being wrong. So what was happening? Was it that I was feeling some of KM's misery? I had a genuine wish to be make things right and to be able to relate to KM. I took responsibility for my feelings, but resented KM for 'reducing' me to such a dark state.

I had a very lonely time, no mobile, or Internet connection, so there was no one to help me sort out my predicament. By the next morning having finished the food I

brought the previous day and as KM was not acknowledging me, I went to the dining car on my own and socialised with the person sharing my table. It was nice to have some normality, although it felt surreal. After breakfast, KM talked to me briefly asking me to stop attacking her. Her comments hit me in the pit of my stomach. I was both astounded and affronted. Panic in the moment about what an allegation of attacking someone could mean for my career as a support worker. Astounded and furious because as far as I was concerned I had never treated her with other than the utmost respect. Hurt, because ‘attacking’ her was the last thing I wanted to do. It emerged that KM was feeling vulnerable, having experienced a stressful situation prior to our trip. I asked KM if she wanted to talk about it, but she said she would be suicidal if she did; her response was cold, impersonal, and direct, causing me great concern. I had visions of her throwing herself off the train. I did not like the way KM spoke to me, which in hindsight, left me feeling hurt, blamed, inadequate, shutout and confused, compounding my sense of injustice. This was despite wanting to do anything to ease her discomfort. Instead, I felt frustrated with her and myself, manipulated and locked in her intense disapproval; feeling I would be 'wrong-footed' no matter what I did.

This compounded my perception of the carriage as a dark and alien space, the other passengers going about their business, oblivious to the friction between KM and I increasing my sense of isolation. KM’s demeanour also left me feeling exposed and out of sync with the other passengers. Rationally I knew I had done nothing wrong, but emotionally I felt a failure, not just in relation to KM but to ‘society’. My mind I flashed into ‘social work mode’, past experience suggested to me that KM was ‘just being dramatic’, an ‘adolescent strop’, but despite this I was unnerved. I had not

expected KM to talk if she did not want to, but I did expect her tell me if something was wrong.

As time went on I realised KM had not eaten since we got on the train. I offered to get her something, but she appeared to ignore me, adding to my sense of helplessness, and rejection. Despite these rejections, I still felt I should have handled the situation differently, although I did not know how, and could not fathom how we had reached such an impasse. On the other hand, I questioned whether KM was some kind of sociopath who just had everybody running round in ever-increasing circles. I began to be judgemental, perceiving her as misusing her power, aggressive and argumentative. Part of the reason for this was that KM seemed composed and self-contained, apart from appearing to me to exude hostility, anger, and disapproval, instead of sadness or pain. This distance between us remained, later I had my evening meal alone and KM went to the dining carriage[20] five minutes before it was due to close.

When we arrived at our destination, four hours late, it was dark and there were no taxis. KM said do not let me ‘get attacked' several times. I tried to be reassuring despite my tiredness and exasperation. I felt she was overreacting, because the fear she expressed did not match her body language or tone of voice. In addition, the streets appeared safe, deserted apart from two couples out for an evening stroll. The train conductor had told me the hotel was nearby, however, the unfamiliar landscape provided few cues as to where it was and I was distracted by KM's panic, which left my mind blank, not helping my sense of direction.

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[20] dining car

Figure 51. Illustration of the difficulty of wayfinding in a featureless landscape. Photo: Google Maps

Had I been alone, I would have asked directions or stood quietly until I had orientated myself. However, despite her panic, KM quickly spotted the hotel and we made our way to it. By this time, I was exhausted and went straight to bed.

The next morning we had to leave early to catch the bus for the next stage of our journey. I found KM outside the hotel. She said she was looking for cats[21] and that I did not understand autistics and she had not been aware of this before the trip. She said this as abruptly as I am writing it here. This did not help my mood, taking me back to my feelings of inadequacy and injustice of the previous day. Part of this was because she did not tell me how I should understand autistics.

The waiting room at the bus station, like the railway waiting room, had fluorescent lighting but this time was without carpet, which made it echoey, and there was no indication of where to go to wait for the bus. KM still seemed distressed, although

[21] KM loves cats and in her country, there are many strays. Not knowing this at the time, I found it surreal.

'put out' would have been a more accurate description. I asked her whether she wanted to continue with the journey by bus or should we fly. She was adamant that she wanted to continue by bus. Eventually the other passengers arrived and we left. The bus and its passengers were so noisy, I wore earplugs. I often use them when there is background noise, as it makes it easier for me to hear what people are saying. I offered them to KM, but she declined them.

On the bus

We began discussing our work, KM had previously recommended some journal articles for me to read, I took them and some other articles I had found out of my bag. When KM saw the other articles, she became angry, asking me why I was reading other peoples' work and not hers. I felt exasperated, put down and desperate at the same time, feeling I was suffocating. I was affronted by her 'telling me what to read' and worried as to how things could be put right between us to re-establish our friendship. This led to an acrimonious conversation during which I did my best to try to diffuse things, finding KM difficult and demanding. This conversation was not helped by the simultaneous noise of the bus engine and on-board video. As the journey continued, I attempted to buy food for KM at stops along the way but everything I offered was rejected.

When we arrived at our next destination, another passenger befriended us, helping us to find a quicker, modern bus to complete our journey. It still had music and I wanted to ask the driver to turn off, but KM would not let me. Eventually, after several hours and some persuasion we got KM to agree to our new friend asking to have it turned off. By this time, it was dark and I was trying to sleep, when KM said that she was afraid we were going to leave her. I reassured KM, as did our new

friend that we were not going to do this, with not much success. At this stage, I would have loved to have got rid of her, and I am sure she picked up on some level that I had had enough. I had had enough of being used, as I saw it, like a punch bag and trying to convince her that she was ok. All my resources of energy and goodwill deserted me.

KM went to the back of the bus to sit on her own and our friend followed. He came and sat next to me later and said that KM was 'much better'. I missed the buses' first food stop as we stopped at a small shop rather than a service area and our friend had to negotiate another food stop with the driver. KM stayed uncommunicative, on the bus while I bought some sandwiches. As the bus moved off again I realised that KM had not eaten either and I had forgotten this, which made me feel awful. However, by this time I was a bundle of resentment, feeling alienated from KM. Luckily the bus made another stop, I found some bland sandwiches which I gave to KM, hardly getting an acknowledgement; although KM did thank me a couple of days later.

In the early hours of the morning, we changed buses again. KM said this bus station was much better, because it was lit with incandescent rather than fluorescent lighting, providing a yellowy light which less uncomfortable for her. I suggested buying more food, but KM was adamant that she did not want any. When we resumed our journey, KM sat on her own, and I felt some tension had dissipated. Most of the train and bus ride had been hell. Dingy train carriages infused with KM's coldness and disapproval had left me feeling isolated and alienated. I only really enjoyed the last few hours of the journey, along beautiful coasts and through forests, when I decided I had had enough and forgot about KM.

When we got to our destination, it was busy and not clear where we could get a taxi. Eventually we found one and I got in with a big sigh of relief, this was short lived. As soon as the taxi started moving, KM rounded on me. ‘Why hadn’t I realised how her senses were going to be affected. Didn’t I realise how much it hurt’. Her ceaseless tirade went round and round, I felt I was being spoken to like an ‘underling’ rather than a colleague. There were degrees of condescension in her voice when she was speaking to me, during most of the trip, however, I had been able to distance myself emotionally, but tiredness had overtaken me and I was vulnerable. KM kept saying I ‘should have known what it would be like’, the implication being I should have stopped her. As far as I was concerned, she wanted to come and she is not the type of person you can stop from doing anything. She had lived for several years in one of the countries we passed through and she was widely travelled. KM had said she wanted an adventure and it was part of her work role, so as far as I was concerned, she should have had enough self-knowledge to know whether she could or could not cope. Despite this rationalisation I felt trapped in the emotional double blind, I described earlier when I discussed KM's rule 'to keep out of peoples’ way'.

Throughout the trip, I had wanted KM to be comfortable and would have done whatever I could to achieve that. However, if KM would not communicate with me and would not tell me what she needed, I could not support her. I felt on one level that I had done something terribly wrong and on the other that her behaviour was outrageous, aggressive, demanding, and patronising. I tried to intervene to defend myself but that made it worse. I was missing the supportive friend KM was when I was at home. As we live some distance from each other, I was looking forward to talking to KM in person and having a lively exchange of ideas on the journey, which did not happen.

Our destination

Our hotel did not look anything like the picture on the Internet, which together with the after effects of KM's tirade disorientated me. Once I was sure, it was the right hotel, KM who had had brought no currency with her, left me to find change to pay the taxi driver. On top of this, our rooms were not ready so we went to the restaurant, and if I had thought the tirade in the taxi was bad, the restaurant was worse. KM told me it hurt when I looked at her. I had no idea of this, during many years of being a support worker I discovered those who found eye contact painful did not look me in the eye and I accepted it. When I met KM previously she had never mentioned it, why now, especially when she was looking at me straight in the eye with such venom. I deliberately, instantly looked away from KM, but this still did not seem to be what she wanted. On and on KM went, near the end she said my mother says ‘when I am bloody, I am really bloody’ as some kind of explanation or apology. I was beyond either; I was doing my best not to cry, looking out the window of the hotel restaurant. I was hurt, humiliated, angry, diminished, and deskilled. Confronting KM, I knew would not work and would have made a ‘scene’; she would not have known what to do and been overwhelmed. It would have been a form of abuse.

I knew I was doing something wrong but could not see what. So, I distanced myself, shutting myself in my own world. Instinct told me to let her ‘get away with it’ a phrase I hate, but which was what I felt at the time. A term used by many of those who share their lives with autistics, and others with a social or cognitive disability, reflecting their authoritative and paternalistic attitudes towards them. I heard KM say she was going to the business centre to send some emails, as she was the loneliest person in the world. I thought let her get on with it, I did not have the energy to reassure her and felt she could not have it both ways, telling me I was awful and then expecting

reassurance. I needed time out; I slept from lunch until ten in the evening. KM did not even call me to have something to eat, and I was starving, as I only had fruit for lunch. When I reflected on what happened I was aware that the majority of the time the people I support seem to like what I do and I mostly get good feedback. What had happened, how had this gone so badly wrong, when I had been looking forward to it so much?

The next day I was downhearted, KM was not around so I went to breakfast on my own, she soon joined me. She was less angry, wanting me to choose some things from the menu, so she could try them before she committed herself to ordering. After a while, she told me not to keep looking away from her to avoid eye contact. She said what she called a passing gaze was not painful as it had no emotional content. However, as I described in the previous section, when I looked at her with a question in my eye it hurt her, for instance ‘are you okay?' I explained I was concerned and wanted to find out how she was. KM then told me off for asking, as she said she did not know, therefore the question was meaningless. She said her mother constantly asked how she was, despite KM constantly telling her she did not know. Now if I want to know 'how KM is' I ask 'are you well' and KM can answer this.

Major issues from the journey:

- The effect of autistic demeanour on emotional, spatial comfort
- Resentment caused by KM's differences in the application of social rules
- The unintentional creation of double binds
- The preference for interaction with machines over people
- Alienation from KM

Analysis of findings

In the grey boxes below are KM's account of what occurred and our subsequent discussions, triangulated with autistic authored accounts and academic research. The same pattern is followed in subsequent chapters.

First, I will explain the findings as they relate to space before going on to give KM's account of what happened triangulated with data from autistic authored writing and academic discourse.

Refining my typology of space

In relation to this and subsequent chapters, I refined my typology to formulate the interactional elements of space as a space in their own right, illustrated in figure 52 below:

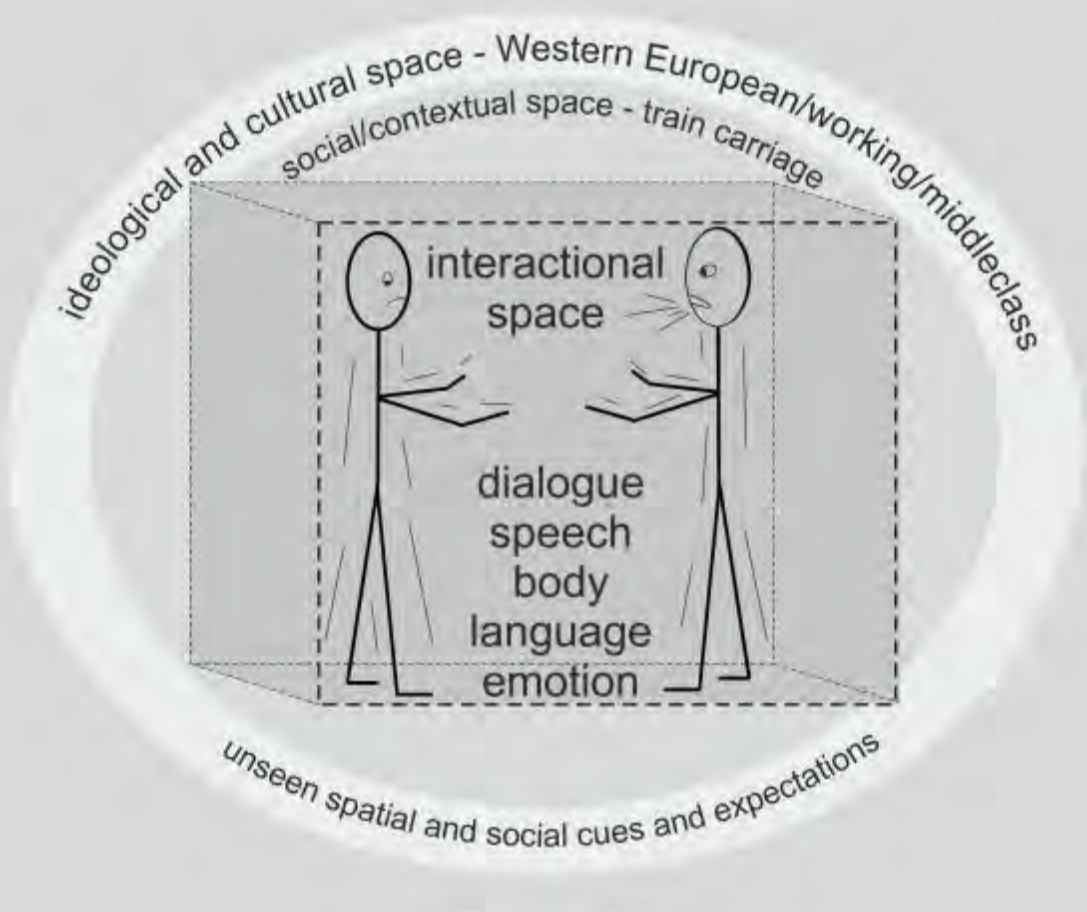

Figure 52. My typology of space applied to this case study

Figure 53, details the dynamics of interactional space, furnished by the bodies of the participants in a similar way to objects in 'physical' space. Just as inanimate objects affect the emotional ambiance of space through their aesthetics, so do people. Often more so, everyone's demeanour is variable as is its impact on spatial comfort as demonstrated in this case study.

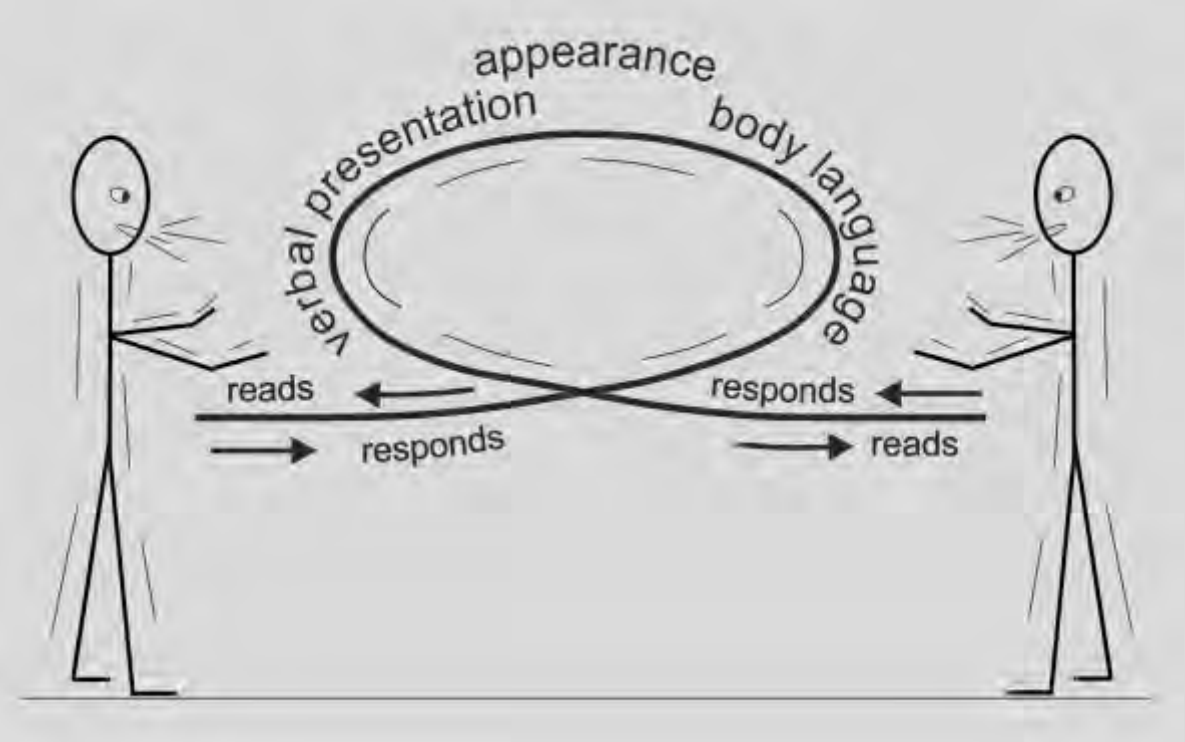

Figure 53. Communication exchange in interactional space

Why understanding the spatial dynamics of the journey is important

This case shows how the demeanour of an autistic person can affect the emotional spatial comfort of others resulting in alienation despite typically developing peoples' best efforts. This can lead to them becoming ever more judgemental, escalating the misery of both.

The journey illustrates how one space, in this case the train carriage is made up of multiple interactional spaces; each group or pair of people creating their own space with its own rules and expectations. In this instance, the interactional space between KM and I was tense whilst outside it, the carriage was calm.

A problematic relationship could be dismissed as social and nothing to do with space. But, as Plimley's students state the 'within people qualities' are crucial to autistics' spatial comfort (Plimley, 2004:36). In this instance, they had a huge impact on our spatial comfort, changing the relatively neutral space of the train carriage into 'dark tunnel'. An example of this is my relearning to ride a bike. The instructor insisted that I ride on a minor through road where I live. On foot, the space is benign, and navigating cars is not a problem, but on a bike, the cars and the space became fearful. However, my instructor was very positive and encouraging, pushing me to do things, telling me I was doing well even when I nearly fell in a heap on the road. This meant the space felt safer even though I was well out of my comfort zone. If my father had been teaching me, his anxiety and impatience would have frozen me and I would have felt defeated. His behaviour affecting me physiologically in similar way, to the effect KM reports below. The bike instructor had less power over me than my father creating a reassuring dynamic. However, in KM's case she could not even tolerate reassurance.

Alienation from KM

I suggest it is important for anyone who lives, travels, or works with an autistic person to be led through the process that eroded KM and my spatial comfort, as we became alienated. The aim of the narrative account is to hopefully stimulate similar

feelings to my own. Now I turn things on their head, by giving KM's account, showing my contribution to her intense spatial discomfort.

The first aspect to note is that KM did not have the choice about the times of day we travelled on the trains and buses. The train to our destination only had one departure a day, which meant it was nearly full, whereas during my stay with KM, described in the next chapter, KM always got the early train, which was nearly empty. Also apart from complaining about noise, KM did not mention the sensory or physical aspects of the train carriage as being problematic. Focusing on the spatial discomfort caused by my presence and the impact of the surrounding countryside as it changed from one culture or environment to another.

KM's account of what was happening

Emotional hyperarousal

When KM and I discussed the conflict that had arisen between us, KM calmly repeated that she had felt attacked by me on the journey, as I was 'creating a constant, emotional commotion', as our discussion continued she used other graphic phrases such as:

'she (KM) had to 'do anything to shut me up, even if that meant me hating her

'she just wanted to stop me doing anything'

'you make one more movement and I shutdown[22] period'

Eventually, it dawned on me that KM was referring to what was going on in my mind not conversation or physical movement. She said this disturbed her space physiologically, just as her hostility was affecting my space. I was only too aware of many emotions passing through my mind during the journey, frustration, exasperation, loneliness, concern, ambivalence, anger, resentment. KM said that normally she can read the emotional states of others well. However, if she is near to shutdown, as she was on the train, and senses many fluctuating emotions in those around her, she cannot read them, potentially leading to a complete shutdown.

The more KM tried to distance me to prevent this, the more varied and intense my

[22] A reminder - people will talk about shutdowns and meltdowns. Shutdowns result in the person collapsing due to sensory overload (Boucher 2009). Meltdowns often appear as angry outburst which the person has no control over. (Smith Myles 2011)

emotions became, creating a vicious spiral of overwhelming and unreadable emotions. KM described the situation as an emergency, where it was more important to shut me up than accommodate my feelings. KM said she was ‘not at all angry’ with me, but at this point, I was dangerous as my feelings of guilt, worry and anger were stressing her out and she had to minimise stress to avoid a shutdown. KM said that she could not recall what happened to start the spiral due to her impaired episodic memory, which I discuss later. However, she says what usually happens is a simple, intellectual issue escalates into an emotional one. Even though there was very limited dialogue, my emotions caused her, to use her words 'spiral' into an emotional crisis.

KM says it is important to understand that conflicts between autistic and typically developing people often begin as intellectual disagreements and become emotional. During this process, the typically developing person often forgets the disagreement’s origin was intellectual, affecting the spatial comfort of both and perhaps others around them. The escalation of the typically developing person’s creation of emotional inferences that were never intended heightens spatial tension. This leaves the autistic person struggling to integrate the emotional dynamics of something that for them is intellectual not emotional. In the example above, KM was not judging me, only wanting to distance me emotionally from her as I was seriously affecting her spatial comfort. Instead, I took the situation personally, feeling my integrity was on the line, when her intention was to prevent herself being overwhelmed by my emotions.

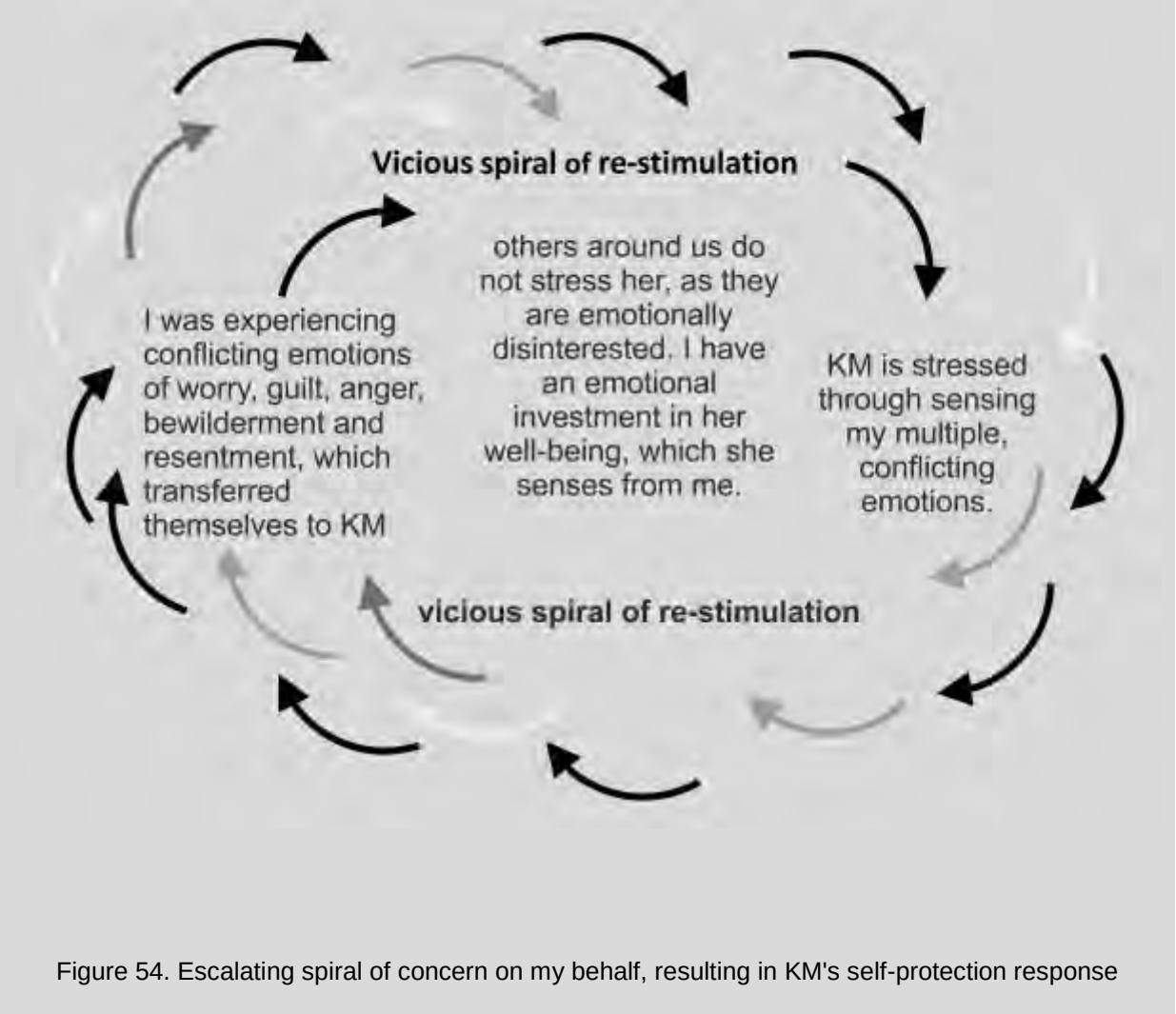

Figure 54. Escalating spiral of concern on my behalf, resulting in KM's self-protection response

KM said she was near shutdown because she was exhausted, making her stress levels rise. She says she does anything to avoid a shutdown, as it is like being stuck in an MTV music video. KM says it starts by her feeling as though someone is shining a very bright torch at her, which is so bright it hurts. Everything becomes hugely painful until she reaches the point of no return, where it becomes difficult to respond. KM said the pain is the worst, when she finally losses the ability to talk or gesture, at this point her vision is poor and it is difficult to move. Similar experiences are also described by members of WrongPlanet, (Brown06, 2010; Pensieve, 2010). KM says she hates the pain, is grey faced and ill for the following 24 hours. Shore has a similar experience to KM, saying that when facing overwhelming emotional conflict, where he senses emotions but cannot name them, his ability to talk shuts down (Shore, 2001:109).

Shore also describes sometimes not knowing where an emotion comes from and whether or not it belongs to him. He says he feels 'fused ' to other peoples' emotions which can make him very agitated and anxious (Shore, 2001:37). He describes a conversation with his mother which was accompanied by an unaccountable feeling of blackness, discovering later that she was feeling very sad (Shore, 2001:37). Members of WrongPlanet also describe extreme sensitivity to the 'moods' of others to the point of shutdown. Hood describes this sensation as the equivalent of unwanted ESP (Hood, 2010). jagatai [original capitalisation] suggests his extreme reaction to others' emotions is because he goes into a fight or flight reaction, when entering situations he has limited skills in managing (jagatai, 2010a).

From her account I realised KM's demeanour on the journey, had been self-

protective. She had distanced herself from me emotionally to prevent my feelings overwhelming her, even though she sat away from me most of the time. The only way KM could distance herself was by alienating me so that I left her alone to allow her senses to settle. Smith describes a similar strategy, pushing people away not because they have done anything wrong. But, because he needs ‘quiet solitude’ to regain his senses and will re-join people when he is recharged, as he also needs company and support (Smith, 2006a). KM also says she needs support and enjoys company. Caldwell has also noticed the tendency of some autistics to push her away; arguing that our presence alone may make sensory demands on them (Caldwell, 2005:88). Markram et al concur with this view suggesting that emotional cues maybe over attended to and frighteningly intense (Markram and Markram, 2010:3).

The effects of hyperarousal

KM explained that when she becomes hyperaroused through not being able to integrate the emotional state of others, she responds physiologically rather than emotionally. Therefore, not sensing any emotion from her other than through her body language, I assumed she was being intentionally hostile and overbearing. Had she responded in a similar way to OP's response to noise, in the previous chapter I would have had some cue that something was wrong. Smith Myles and Southwick illustrate the absence of emotional cues in autistics in their case study of ‘David’ who says when he feels confused he becomes frightened and lashes out physically (Myles and Southwick, 2005:105).

KM who describes herself as a language savant, responds instead with a verbal tirade and hostile body language. With these as the only indicators something was wrong I became judgemental rather than empathic. KM would have got an empathic response had she burst into tears which is what Baker describes doing when she melts down (Baker, 2009).

The effect of emotional age

KM suggested the reason for her demeanour could also be that her emotional age is five or less, so she is unable to integrate emotions at Ben Shalom's level 2 (Ben Shalom, 2009:589). She said that you would put an over tired one-year-old baby to bed, or if you found a small animal in a trap you would not stare at it or ask it if it was all right as that would make it more frightened; you would leave it alone to calm down. I was never aware of staring at KM; if I did look in her direction, my gaze was repelled by her 'hostile' body language, which was how her hyperarousal manifested itself to me. On reflection, it might have been my emotions rather than my eyes that were 'staring' at KM.

KM says she is hyperaroused most of the time, needing a small, warm, dark place where she can be alone. At the hotel, she spent a lot of time in the fire escape stairwell and the computer centre, as there was less light and noise from the air conditioning. Other autistics also like dark spaces, one person describes sleeping on a mattress in a completely dark, walk-in closet, the clothes insulating against noise (FJP, 2010; Schiman, 2009). Age 1600 describes the space they would like to create:

> I always thought about opening a restaraunt or store where the lights are dimmer, theirs only soothing noises in the backround, nice and open, every corner you turn, theres a room where you can go collect yourself... Or a restaraunt were it has a part of it secluded for people who are mentally disabled, where everything accomondates their needs, and so you can be yourself, and not have to worry about the stares or the people talking about you behind your back. I would do anything for all of that! [I have retained the author's spelling] (Age1600, 2007)

The effect of geographical space

KM said part of the reason for her extreme hyperarousal was because we were in 'a third world country'. She said this several times and I dismissed it without thinking, I could not see the connection, a large part of the route passed through an affluent country and her demeanour had been the same in both countries. I felt KM was 'making a fuss over nothing', the towns we passed through had solid houses; most places had air conditioning and well maintained toilets. The road at the end of the journey was rough, but we had luxury coach with a uniformed driver. The streets around our hotel were relatively modern and spotlessly clean. By nearly dismissing what KM told me, I almost lost significant data. However, on-going discussions and my pursuit of an equal relationship with KM meant that eventually I was able to challenge KM's conception. I asked her why she appeared to be just as miserable in the 'affluent country' as she was in the 'less developed country'. KM said she is very good at picking up ambience; even though we were still in an 'affluent country', she picked up the changes in architecture and culture as we neared the border. Whereas

I only saw a stream of almost identical towns, KM perceived the people as being louder and more unpredictable, when she had assumed the culture of the country we were visiting would be similar to her own.

This was an occasion when taking a risk, exploring the hyphen/difference and working on an equal basis, with KM and the other participants, new issues emerged. It is unlikely they would have surfaced using traditional research methods, such as formal interviews, questionnaires or quantitative methods. I had almost preconsciously dismissed what KM was saying, judging her instead as 'being demanding'. The tendency of typically developing people to dismiss or suggest that autistic experience is exaggerated was discussed by Sinclair at Autreat 2011; the feeling of the conference was that this tendency is due to historically determined prejudice (Sinclair, 2011).

To return to KM, I discovered she is extremely sensitive to changes in culture and geographical space. She says she finds space in developing countries difficult to process as there is more, noise, colour, and visual clutter, whereas in 'affluent' countries, the landscape is more uniform.

Figure 55. Shows shops with goods spilling out haphazardly into the street. Photo: David Mason

Figure 56. A modern shopping centre, preferred by KM because of its simplified, clean lines and repetition. Photo: Thomas-Gast64

The effect of space in the new country

Long after the trip KM told me, she felt completely lost at the border, as it was so ‘nondescript’, she felt we would never get to our destination. The border was in what was desert to her, whereas it was fascinating scrub to me. I expected a desert to be just sand. KM said she felt like vomiting and running away. This appears an extreme reaction, however, prospect/refuge and habit theory argue denuded environments trigger innate, evolutionary impulses. This is because they do not contain representations of necessary elements for human survival. For instance the ability to see without being seen, the presence of water, shelter and food (Appleton quoted in Maulan et al., 2006:28; Montgomery, 2010:9). Ben Shalom’s typology of autism argues that those who are Type 1 rely more on unconscious, animal-like sensing through habit and skill. This and prospect/refuge theory suggest that KM’s panic was congruent with the environment she was presented with.

Returning to the double bind

I could not have foreseen the effect that a new country would have had on KM or ‘how her senses were going to be affected’ or ‘how much it’ would ‘ hurt’ ‘ or ‘known what it would be like’. My assumption was that she had the foresight to gauge this for herself. Therefore, I was astounded when she suggested I should have known, with the implication that I should have prevented her from going. However, KM is not the sort of person it is easy to stop doing anything, she is an adult and can go where she chooses. On the other hand, she like all of us has vulnerabilities and as a kind, caring, empathic person, and competent professional should I have done something to prevent her discomfort. Therefore, I felt blamed and defensive, trapped in an

intense emotional double bind, far more uncomfortable than the one in response to KM's injunction 'not to get in people's way in McDonald's and the waiting room. I knew I was powerless to challenge her past decision and resolve her discomfort in the present, which caused me considerable heartache, despite my attempts to rationalise the situation.

Episodic memory and imagining the impact of the journey

My astonished and defensive professional reaction to KM's assertion that I 'should have known what the journey would be like for her' was that 'she was not taking responsibility'. I felt she should have weighed up whether the 'adventure' and its role in her career progression compensated for any negative effects. Such foresight requires the remembering of past events to inform current ones. KM said she could not do this, as she has no episodic memory. An important element of this is autonoetic awareness, the individuals' ability to remember themselves and their actions in past events, to inform future ones (Lind and Bowler, 2008). In KM's case she says does not remember past events and her role in them unless they are linked to an emotion she experienced at the time. This also relates to her ability to visualise past events, corresponding with her disunified perception of space and objects.
When KM visualises past events she sees what she terms 'raw items' which are rarely pictures; in contrast to Grandin who famously 'thinks in pictures' (Grandin, 1995).

As our discussion intensified, she said she uses both emotions and body feelings in order to do 'visualisation', through her body. In the case of our journey, she could

remember her emotional reactions to events, but not her part in them. For KM and other autistics with impaired episodic memory, this is to the extent of being unable to visualise places that the individual visits regularly (Boucher, 2007:261; Faran and Ben Shalom, 2008:87ff; Toichi, 2008:156). Therefore, KM could not use previous experiences of living and travelling abroad to visualise how the journey would affect her. Lack of episodic memory also means individuals cannot remember the social and spatial cues of previously visited spaces to transfer to similar situations in the future.

To compensate for this, KM says she relies on facts, practice, and memorisation of rules in order to manage her spatial participation, i.e. semantic and procedural knowing (Jordan, 2008:295). Procedural memory relies on skills learned through extensive, conscious practice and habit, relying less ‘on remembering and more on knowing’ the equivalent of functioning at Ben Shalom’s level 1. Whereas episodic memory relies on preconscious integration of events at level 2, and semantic memory operates at level three (Ben Shalom, 2009:589; Bowler et al., 2000:295; Gardiner, 2008:6).

Boucher discusses similar strategizing by her participant JS, who remembers past events by memorising conversations (JS quoted in Boucher, 2007:626). An example of KM's use of semantic rather than episodic memory was when we were driving through a town KM had relocated to. She said she remembered walking past the school the day before and I asked how she did it without episodic memory. She said she remembered as she could process the letters on the school’s sign, the English

alphabet only having twenty-six letters to memorise. This was demonstrated when we visited her friend who KM had visited several times, she could not identify any landmarks to direct me, although she recognised the place names on signs.

The question ‘how are you?’

As we saw, in the narrative of the journey I was taken aback by KM's response when I asked how she was. When I discussed this in depth with KM, she said it felt unnatural to think of ‘herself’. She described it as being like toothache, the tooth hurts when it is left alone, but if you touch it, it makes it worse. KM said the question ‘how are you?,' forced her to think of herself, which if she was 'sad', made her sadder, sometimes stimulating other negative emotions that were not there before. Jones et al in their study found that the predominant emotion of their participants was of unpleasant emotional experiences (Jones et al., 2001:399). KM said the re-stimulation of unwanted emotions by being asked how she, is compounded by her difficulty in switching feelings.

Therefore, if the question makes her feel sad, it is difficult to switch back to feeling happy. With the result on the journey that once she decided to alienate me, it was difficult to return to being friendly. Grandin and Beadle, say they find it hard to switch emotion, even when they know they need to such as stopping laughing (Beadle, 2011; Grandin, 2011). This observation is also made by Smith Myles and Southwick and Mazefsky et al, who attribute this to attention-shifting issues, which may lead to overly focusing on distressing stimuli (Mazefsky et al., 2012:93; Myles and Southwick, 2005:35).

Letting people get away with it - what professionals have to say:

Smith Myles, says that autistics have issues with self-calming, their demeanour not being intended to upset people (Smith Myles, 2011). KM was out of her depth on the journey and felt dependent on me. She had not been able to visualise the journey because of her lack of episodic memory. Not realising this I became defensive, rationalising that an intelligent woman like KM should have thought through the issues the journey might present. However, I knew on some level that I was missing something. KM said she could sense that I was caught between understanding and not understanding.

I was hooked because I felt KM was showing intentional disrespect to me and I did not want to let her ‘get away with it’, an infantilising phrase I hate. As a support worker, I could be seen as 'letting people get away with it’ all the time. However, my experience shows that maintaining open communication, genuinely trying to understand and work alongside people, means they eventually pick this up and respond to what is required. In doing so I only aim to achieve 'compliance' to issues relating to health and safety, the protection of property and civil rights, making sure that bills are paid and clothing and household items do not deteriorate to the point of no return, and the person achieves the things that are important to them. Smith Myles discusses the 'myth of coddling', the equivalent of 'letting them get away with it', arguing that when autistics are going into melt or shutdown those around them have to recognise that autistics are in control and use distraction rather than confrontation (Myles and Southwick, 2005:35). Direct confrontation can result in autistics being more at risk, for instance of criminal prosecution, hospitalisation

and/or the ‘chemical cosh’ (Smith Myles, 2011:105).

On the journey, although I knew KM pretty well, there was no way to create a distraction, I just had to remain as calm as possible and try not to cause further distress. KM eventually got what she wanted, which was for me to go away emotionally which I eventually did. Smith Myles advocates a similar strategy; to remain calm, use a quiet voice, prevent a power struggle, and disengage emotionally (Smith Myles, 2011). Peeters, similarly argues for the use of humility, understanding, and tolerance when engaging with autistics (Peeters, 2011).

My expectations of KM’s demeanour

Until I undertook the journey with KM, I had not worked on an equal basis with someone who was autistic, despite having autistic friends. I had not experienced what I perceived as hostility and disrespect from them or those I work with as a support worker. Those I work with are often in control of the situation in ways that I would rather they were not. When I do not know the person, I have no expectations except that we will spend our time as amicably and safely as possible and complete tasks assigned us. If I do know them, obviously I will have some expectations informed by past contact. Sometimes people are friendly, other times they may not be. However, there is professional distance and limited emotional connection. Whereas in the case of KM, I felt we had established a friendship and working relationship. Therefore, I expected her to be friendly, animated, and have lively discussions, whilst I was aware that the sensory demands of the trip might mean she would soon tire or may collapse. I had witnessed this previously and was ready with a strategy.

What I was not prepared for was what I perceived at the time as hostility, aggression, and disrespect and its effect on my spatial comfort. On one level, I was aware that these were my expectations not KM's, but this was overridden by my feelings of hurt and rejection. This resulted in a defensive, judgemental stance that assumed KM was being deliberately hostile and disrespectful. KM says she knew I was distressed, but was so overwhelmed trying to deal with the processing of our combined emotions, she could not do anything about it. Therefore attempting to adjust her demeanour to meet the social nuances of politeness that indicate respect was beyond her. KM says she usually compensates for her differences in the integration of social norms such as politeness (level 2 of Ben Shalom's integratory theory), by making people feel good using semantics (the equivalent of level 3) (Belmonte et al., 2004a:9229; Ben Shalom, 2009:589).

I did not 'feel right' about what happened during the journey. I was partially aware that I had certain expectations of KM. Goffman describes these as ‘obligations’ and ‘expectations’ whereby individuals are expected to behave in certain ways to receive certain behaviour back (Goffman, 1972:49). Goffman illustrates this using the example of the expectations doctors and patients have of each other. In this case I expected KM would be animated and chatty, and if she was not happy, she would tell me what was wrong and what if anything I could do for her (Goffman, 1972:49). Because she could not do this, I felt intense frustration and anxiety, I was under no illusion that I could help, but at least I would have known what was going on and whether I needed to change anything I was doing.

Goffman discussing our social expectations of others says that we transform our

social expectations of peoples' demeanour into 'normative expectations'. He says we are not usually aware of what they are until they are not met, creating imaginary social identity for that person. When the person does not meet our expectations then we discount them (Goffman, 2006:131). I did this through the judgemental stance I took towards KM's demeanour, because she did not meet the fantasy image I created. In doing so, I had made her responsible for turning the train carriage into a horrible, frightening, dark space, whereas my expectation was that although the journey could have been uncomfortable, boring, or frustrating some of the time, it would also have been fun. Instead, my response to KM's demeanour was to question whether KM was autistic at all and whether she was some kind of sociopath. Part of this could have been fuelled by an inherent cultural expectation of a passive, malleable, disabled person, despite the fact that all my disabled friends are none of these.

I had not wanted to get into such a conflictual situation with KM. As a support worker, I have seen many similar situations, but luckily something, somewhere in my psyche told me this was not right and it was not totally KM's fault.

Although it was not my intention at the outset, the journey illustrates how I used sharing my sense of spatial comfort or not with the participants, to understand how the dynamics of interactional space affects autistics and those sharing it with them. The narrative above and its analysis illustrate how autistic demeanour affects our emotional spatial comfort and can lead to conflict. Autistic people often come off worse as they cannot integrate the social and spatial cues to present the required demeanour fast enough to defend themselves. This is exacerbated by their social

differences being associated with cognitive impairment and mental health issues by typically developing people. Shore argues typically developing people respond to conflictual situations with autistics either by being supportive or bullying (Shore, 2001:113). The behaviour of typically developing people to autistics, who share their space, often being justified by the autistic person's 'behaviour'. This is often done with no reflection on the behaviour of the typically developing others sharing the space. Autimom argues:

'To be fair, for every antecedent-behavior-consequences form sent home for a child, there should be another one sent home for the teacher' (Autimom, 2006).

Part of this lack of reflexivity, I would argue, is due to the often-extreme emotions triggered by autistics in those who share space with them. This is because autistics often unwittingly infringe the ideological and contextual expectations shaping the social and spatial cues of interactional space. This as I have illustrated in the above narrative disrupts the understanding of the spatial and social cues of interactional space. The result is that typically developing people feel insecure as they no longer know the rules, and therefore the space becomes unpredictable, leading sometimes, as in the case above, to acute spatial discomfort. Part of this discomfort may derive from the threat it presents to the authority, professionalism, and personas of those sharing space with autistics.

All three challenges involve a potential 'loss of face'. For instance for those who want to control the demeanour of autistics and/or the space, and/or if someone sees themselves as understanding and helpful and they are shown to fall short, but do not quite understand why. This is exacerbated as many people supporting, managing, or

teaching autistics feeling superior to them, just because of their apparent nondisabled status and the links between autism, mental health, and cognitive disability. However, the intellect and demeanour of the autistic person may threaten their superior status, and whereas the typically developing population often modify their behaviour so they are not a threat to those in authority, autistic people are often unable to or do not see a need to do this.

This can result in a defensive and punitive overreaction by those in authority to regain face and control of the autistic individual and of the space. This can take the form of institutionalised bullying where those who share space with autistics respond defensively and reactively to their demeanour. Sometimes they want to 'get' the autistic person because they have been shown as 'wanting' and sometimes this is manifested in restrictive regimes, negative reports and withdrawal of services as will be seen later in this thesis. In my case, I also felt punitive towards KM because she had ‘made me feel miserable’, even though I am fully aware she is not responsible for my emotional state, until we were able to discuss what had happened. In these situations, the space becomes even more unpredictable and stressful as both sides attempt to take control.

Countertransference – my extreme emotions as a response to those of KM

My feelings of desperation and misery on the journey were so intense, I knew they did not completely belong to me. I have travelled widely including using the same train service we travelled on and was used to the mixture of tedium and unpredictability, so I felt something else must be going on. The only way I could explain it was using Freud’s theory of countertransference (Rossberg et al.,

2007:226). This suggests that the client's emotional state is transferred to the 'therapist' during therapy. The effects of countertransference were confirmed long after the journey when KM and I went for a meal. We had begun the meal when suddenly KM's face went grey and her face appeared to elongate, she said 'you are asking too much, I can't do this'. My heart sunk, my initial reaction was 'we (myself and another mutual friend) are only expecting you to sit at the table while we eat until you go to work and you chose to come here'. Despite the knowledge gained from the journey, my discussions with KM, and having known her for a considerable time at that stage, I still had the same emotional reaction – feeling blamed and defensive. I suggest this is instinctual, we are innately programmed to react in certain ways, and these have a negative impact on autistic people we share our lives with. LeDoux argues most of what occurs in the brain during an emotion is outside conscious awareness, emotional arousal dominating and controlling thinking which he argues is innately conditioned by human survival needs (LeDoux, 2003:267, 303, ch 6-7). My instinctive response conditioned by the need to be surrounded by those who are co-operative to enhance my survival ability (Buss, 1995:9).

The threat to my reference group membership

My defensiveness largely occurred because I assumed that instead of KM seeing me as not able to appropriately deal with that situation, she viewed me as globally insensitive and incompetent. I was so shaken, I felt everybody was seeing 'how awful' I was being, affecting my spatial comfort. Much later in our discussions KM suggested that when typically developing people cannot meet each other's expectations, this preconsciously threatens their membership of the reference group

they aspire to join. I aspire to being a competent and conscious support worker, researcher, and designer with a social persona to match. Not being able to relate to KM threatened my aspirational membership of these groups and my social persona as someone who is responsive to the requirements of others (Holton, 2004:514; Shibutani, 1955:563). This could account for my extreme anxiety and defensiveness. Attempting to make sense of this led to what was for me, risky territory, during KM and my discussion of the data.

Taking risks, employment of the hyphen, rigid adherence to working on an equal basis and intensive member checking during the rest of the case studies was crucial. Without this continual, detailed scrutiny, huge amounts of valuable data could have been missed. I constantly had to trust the participants, the process, and myself to notice the questions that lodged themselves almost preconsciously in my mind, until I eventually addressed them with the participants. When I did this, they were usually the key to important data.

Section 3: Stay with KM in her apartment

In this section the body of the narrative of our go-along is written directly on the page and the participants' and my commentary and analysis is in the grey boxes.

The narrative shows clearly how I made inaccurate assumptions when sharing space with KM. Within the grey boxes I explain how, based on her demeanour and spatial functioning, assumptions were made. This is then triangulated with autistic authored and academic writing.

In this section, I describe aspects of my stay at KM's apartment. A significant focus of the discussion in this chapter is the effect of KM's space on me, illustrating how anyone can become disorientated in spaces where many socio/spatial cues are different or absent. These are interspersed with data from go-along's involving travelling, visiting KM's workplace, and going shopping.

I felt disorientated from the moment I arrived at KM's apartment. It was dark and I arrived by taxi, again the apartment bore no resemblance to its picture on Google maps. The space was not reassuring; apartment blocks crammed together with poorly lit overhangs shading neglected gardens, which KM said was how she and the other residents liked them. The stairs to KM's block were in darkness and I could not recognise which were light switches and which buzzers. After pressing several and getting no light or response from the scruffy apartment doors, I doubted I was in the right place. I used my mobile to ring KM although I was worried as to whether it would work, luckily KM answered, giving me directions to her apartment. I found the light switch, but could not make it work; I hoped KM would have the door open so her light would show me where to go. However, she only opened the door as I arrived, to prevent her cat escaping. We said hello and I slid inside.

KM invited me to sit down next to her on a mattress on the floor. We chatted away about my journey and my visit as I took in my surroundings. KM told me I would be sleeping on the mattress we were sitting on, and the jumble of bedding next to us was mine, although we would move it to another room. She gave me a choice of two rooms; one was cat proof where KM kept the things she did not want her cat to damage and I could do the same providing I was careful to keep the door shut, the room had no light. The other room was smaller, not cat proof and subsequently I discovered it also had no light. KM said I could sleep there if I kept the belongings, I did not want damaged by her cat in the other room. The apartment looked bare as though someone had just moved out rather than occupied. I took reassurance from not being able to feel the floor beneath the mattress with my sit bones, which told me the mattress was dense enough to cushion my hip.

I chose the small room as it had two windows and was on the outside corner of the apartment, whereas the other room was sandwiched between the bathroom and the room I chose to sleep in. The room was rectangular containing only a chair and printer. The chair reminded me of van Gogh's picture of his bedroom in Arles. This association made the space more reassuring even though its white walls bore little relation to the room in his painting.

Figure 58. The room I slept in reminded me of this painting: Vincent's Bedroom in Arles. Photo: http://www.artilim.com

Whereas the alternative bedroom had no associations, only having one heavily shuttered window and seemingly random contents; a rolled carpet, a box of cleaning materials, some crockery, a small rucksack, and extra paper for the printer. The room was also larger but I could not make enough sense of the space and its contents to sleep there. I quickly put my possessions in there, May, KM's cat was already attempting to sharpen her claws on my new suitcase. The smaller room, felt more manageable despite not being able to shut the door due to its dropped hinges.

KM had not brought food for me or made a meal, telling me she had rejected her mother's offer to provide something, thinking I would be tired and not want to eat. I was starving hungry, and had only eaten biscotti that day, avoiding the airline food in anticipation of trying out something new. I did not mind there being no food, but what I had not considered was that the shops would be shut that day due to religious observance. KM said she had apple purée, yoghurt, and Matzos, I needed more, so we shared some of the Stilton I had brought for her mother with the Matzos[23].

KM looked tired, she said she was usually in bed by six and by this time, it was eight pm. So, I suggested we went to bed. I felt very strange, not only because I was in a new country. I have travelled widely, staying in all sorts of situations, the nearest to KM’s apartment was staying in a hotel that was once a shopping mall. I slept in a bedroom that had previously been a shop, although sparse, there were enough spatial cues to orientate me in the furnishings. Whereas KM's apartment and her demeanour provided few subtle or concrete socio/spatial cues to orientate or nurture me, leaving me feeling disconnected from her and her environment. I have often stayed in sparse religious houses feeling connected to the community through their simple organisation of space and well-loved objects, which indicate their culture, interests, and the expected demeanour as illustrated in figure 59.

[23] Matzos are a kind of cracker

Figure 59. The chapel at Alnmouth Friary, sparse, but creates a sense of connection through the simple, intentional organisation of space and well-loved objects. These indicate the community's culture, interests, and the demeanour expected. Photo: Society of St Francis

However, in KM's apartment I had no sense of connectedness. I felt on a limb with no spatial cues to anchor me to KM or her space in a similar way to her experience of the desert in the last section. KM had previously explained to me that she had few things in her apartment to minimise sensory and motor processing. Despite this, I had not considered how this might affect me, including the possibility of not being able to buy food. This is a similar situation to that faced by many autistic people who cannot choose where they live or who they live with and have their freedom restricted due their perceived support requirements.

I got ready for bed. I was already feeling cold so I asked to make a hot water bottle, which I thought I was mad to bring, KM living in a warm climate. The water in the tap was just hot enough to warm my feet. Thankfully, the bedding was warm and smelt clean. It felt very strange, trying to work out which room to keep things in and where to put them, with no light in either room, relying on the dim light from the living room. I could not see anywhere to put anything, apart from the chair and the floor, which

was quite disconcerting despite my experience of camping. I discovered three shelves in the corner the next day, which helped. I closed the door of my room as far as it would go while I changed, but otherwise kept it open, as I felt claustrophobic even with it partially shut. I could see the patio of the apartment next door with its familiar contents of table, chairs and plants, providing a sense of normality in what I found was an unnerving situation.

Before we went to bed I asked KM what time I should get up in the morning and she said the shopping centre, where we could get food would open at nine. She also said she needed to print an article that morning using the printer in my room.

When I got up, I went for a shower; it and the bathroom were grotty, dark and stained more than dirty. Barring my way was a telephone cable, lying across the full length of the living room floor, which meant I had to step over it every time I went from my room to anywhere in the apartment. KM never tripped over the cable as she had memorised where it was. She did not move the cable, even though most of the time it was unconnected, in order to save her motor processing power. KM used the cable to connect to the internet when she used her computer, subsequently I learned that the majority of the time she did this using her phone. Thankfully, I did not trip over or pull the cable out of its socket.

As soon as I shut the bathroom door KM told me to leave it partly open as her cat May uses it as a toilet. I recoiled from this, vaguely remembering a telephone conversation where KM seemed to suggest May was using the bath as a toilet. I later discovered KM was training her to use the small-uncovered drain in the bathroom floor as a toilet. Whilst writing this up I discovered kits on the Internet for training cats to use the bathroom toilet. This and the fact that May was a house cat was

uncomfortable; I equate cat litter to toilet paper which I culturally cannot do without and freedom as a basic right.

I was beginning to learn the rules of KM's space. Surprisingly, I found having the door slightly ajar did not cause me too much concern. KM said she would not look and I had no reason to disbelieve her. Her matter-of-fact manner told me she just wanted May to be able to go to the toilet. I set out my possessions; electric toothbrush head and interdental brush in a plastic case, thank goodness, so they would not make contact with the basin. Towel over the edge of the bath, arranged so it did not touch the floor; I would rather it had not touched the bath either, but there was no nowhere else to hang it. The small towel I usually use as a bath mat remained unused, as I did not want to put it on the floor. Everything was placed to have as little contact with its surroundings as possible and I got in and out of the shower as fast as possible. I did not dry my feet in the bathroom, partly at the thought of May using it as a toilet, but also feeling I might as well let them dry on the way to back to my room. The floors were worn terrazzo tiles, a composite of cement and granite. Despite this, they were clean. I went back to the room, I was going to say my room, but it did not feel like my room or a bedroom. It felt alien. I closed the door as far as it would go, enough for privacy and got dressed as quickly as I could, to re-establish my persona in my day clothes.

Getting up and going to bed were a major chore, my possessions divided up between two rooms, nowhere to put anything and the grubby bathroom, compounded by cold; it was between 5 and 13 degrees C for at least two days of my stay. My hair dryer provided some warmth while I dried my hair. I negotiated its use with KM who was more concerned about May's reaction, than its effect on herself.

Coming into my bedroom

At nine o'clock on the dot KM came into my room without knocking, I was still dressing, and somewhat surprised. The door was still shut as far as it would go, signalling as far as I was concerned that I wanted to be private. However, it seemed KM was responding to what I had said, rather than spatial cues, such as the door being closed and my moving around to indicate I was still dressing and she needed to wait a few more minutes to print her document. I indicated this but KM appeared quite put out, which she did not hide. Once I was dressed, KM used her small laptop, sitting on a wooden chair outside the door of my room, while she printed her article, which she then went back to bed to read. She said that the chair was her office.

Lunch with KM's mother

KM's mother rang, inviting us to her home to for a roast chicken lunch. Relieved at the prospect of a hot meal and some kind of normality I said I would love to go. KM told her mother this in her first language, which I do not understand so I could not follow the conversation. Mid speech, KM switched to English saying her mother was angry with her, and wanted to know if we were going to the shopping mall or to her apartment for a meal. Exasperated, KM said she could not understand her mother and asked me to speak to her. I told her mother that I would love to have lunch with her, asking if we there was time to go to shopping mall beforehand. We had a rather garbled exchange, but I learnt that the shopping mall was nearby. I also discovered KM had forgotten to ask me the night before if I wanted to go for lunch with her mother so she could defrost the chicken. KM's mother asked to be passed back to her. They seemed to have a heated exchange, KM putting down the receiver saying her mother was angry and did not want to see us until Tuesday. I was intensely disturbed by this altercation, which surprised me. One reason was that I had hoped

KM's mother might provide a bit of warmth and stability during my visit if I needed it. Instead, I felt the loss of the prospect of lunch and social interaction acutely, feeling locked in KM's physical and psychological space, isolated, and abandoned. I could not visualise 'anything nice' beyond that moment. I was hungry, no breakfast was on offer, I had lost the chance of a chicken dinner, some company, and faced the prospect of sitting on the apartment floor all day apart from a visit to the shopping mall. The two wooden chairs having no arms and there being no table to lean on, meant the floor was a preferable option.

Going to the shopping Mall

To get to the shopping mall we walked through a private park. KM had a pass, she kept this in her pocket in a small ziplocked plastic bag with her credit cards. I have never seen KM use a purse or coins the entire time I have known her as it saves processing power to use credit and debit cards.

The park has an undulating landscape, grass, trees, and flowerbeds, unlike much of the rest of the country. KM says she likes the park when it is dark. She said if it was not for the short cut through the park it would be difficult for her to function, the route leads to the station and a small shopping mall.

Range

KM said the mall consisted of a pharmacy, supermarket, stationers, bank, and two restaurants. I saw almost nothing apart from the supermarket, the food stall, pharmacy, ATM and coffee shop, as KM did not window shop or go anywhere except directly to the supermarket, food stall and back to MacDonald's.

KM said she rarely went to her town centre, because it visually overwhelmed her whereas the mall was easier to process. She said she only the used supermarket and pharmacy, but this was problematic due to the distance from her apartment meaning she could carry very little. KM said her mother got frustrated with her because KM often needed items from the chemist and the supermarket, but would only have enough energy to process one shop. KM said she also relied on the small local shop at the end of her street.

The supermarket

Here, KM went straight to the milk products, getting what she wanted, without asking me if I wanted anything or getting a trolley for the shopping. I was lost as I was not familiar with the layout of the supermarket and was looking at the fruit when KM was ready to go. I quickly asked KM what we were going to have to eat for the rest of the day, i.e. what would there be for me to eat, knowing from experience that KM would probably just eat cheese, milk and yoghurt. I wanted a wider range of foods that I would pay for. KM got impatient with me as I did not know where anything was and started to ask her. I was feeling pretty disorientated and shaken both from the demands of staying in her apartment and her altercation with her mother. This made it difficult for me to decide what I needed, especially without browsing, which KM obviously was not going to do; it appeared her energy was running out fast. I understood this, nevertheless, I was thrown by her impatience and being in unfamiliar surroundings.

Finding shop assistants

I quickly decided salad, tins of tuna, and fruit would both fill me up and last for several meals and days if necessary. KM managed to stop a shop assistant to show

us where they were. I later realised her difficulty in scanning for people had caused her to panic, which I mistook for impatience.

As we neared the checkout, I discovered I had no currency in my purse. I had paid more for taxi than I had expected the night before, and had left the rest of my money in my other trousers. I thought I would get money from the ATM in the shopping mall, but it was not working. This meant I had no cash for the takeaway I was looking forward to from a stall outside the supermarket. I was embarrassed by having no cash and having to admit my error to KM, who also did not have much. This meant we shared the takeaway and a misunderstanding led me to choose one that only had yoghurt filling, so I was still hungry. As I had no money I could not go back to get something else. I felt really silly, impotent, and dependent. I worried whether I would have to depend on KM for cash throughout the trip. This would not have been a problem as she has borrowed money from me previously and I would have done as she did and paid her back by PayPal. However, I was frustrated and ill at ease, as I usually have no money worries when I travel. This led to further panic as I worried whether my cards would work, even though I had informed the issuers where and when I would be travelling. I worried whether my cash would last. KM had told me the amount to bring and suddenly it seemed to be not enough. I just wanted my own money and obsessed about it until we got to an ATM on the way to KM's work the next morning. By this time, KMs energy was running out so we went and sat at one of the tables outside McDonald's. KM preferred this area to that of another much more comfortable outdoor cafe around the corner, that had music. The tables by McDonald's were unsurprisingly empty as they were out of the sun and consisted of black seats attached to the tables, grey paving and no music, which was why KM preferred it as it required less processing.

After our takeaway, we returned to the apartment, where I faced the prospect of sitting on the floor for the rest of the day. We talked for a short time during which KM's mother rang to invite me for lunch, which I happily accepted. KM said she was too tired to go. It was a relief to go to her mother's conventionally furnished apartment, have a good meal and a comforting chair for my already sore bottom. KM's mother said she was worried because KM would not have any modifications to her apartment and had not bought furniture for it. She said this was the first time KM had worried them, as KM had always got scholarships and jobs that were the envy of others of her age group. After we had eaten, KM's mother had to mind her grandchild, so I returned around three o'clock, to sit on the floor, alone, as KM, tired after the shopping expedition, went to bed. She provided no indication of whether she would get up or whether we would have an evening meal. I found not knowing this both surprising and disturbing. I felt in limbo together with a sense of doom, not wanting to go out as I would disturb KM by needing to be let in when I returned, and more importantly, I felt it would reduce the impact of KM's space on me.

I was uncomfortable sitting on the floor, having a bad back and shoulder. I did not want to sit on the mattress as it was in the bedroom and it was too tempting to go to sleep and then not be able to sleep at night. I found another pillow on the floor that I hesitated to use, worrying that KM might not like it being moved. I sat on this on top of a partially rolled up carpet, leaning my back against the wall.

Analysis: my reflections

As before, my reflections are in grey boxes to distinguish them from the narrative:

When I analysed this data I realised that the usual discussion, which provides social cues as to what was and was not acceptable in KM's space were not apparent from KM's demeanour or her apartment. Socio/spatial cues are communicated through a mixture of verbal interaction, body language, layout, and aesthetics, in this case through the furniture and possessions of its owner. From these cues, those sharing the space balance each other's requirements and the demands of the space. In this case, the flat had no central heating and it was winter, so despite the warming potential of the air conditioning I was always going to be cold. However, I was reassured by having earlier negotiated the use of a hot water bottle with KM, meaning I had my own heat source.

This was important because KM does not use her air conditioning for heating or cooling. I later discovered that although KM is often very hot or cold, she prefers it to the differentials in heat and air pressure produced in the apartment by the air conditioning, which places extra processing demands on her entire body. In addition, KM also cannot stand its noise, which she describes as 'shrill', whereas I perceive it as a low, but annoying hum. This illustrates the extreme sensitivity of KM's hearing, despite KM not following her doctor's advice to have her ears syringed.

Balancing each other's requirements and the demands of space requires those sharing space to be able to read each other, and adjust their demeanour accordingly to create social and spatial harmony. For instance, an implicit 'I usually do it like this - are you ok with this?', invites the other person to indicate whether my actions are

acceptable or not.

In this instance, I had no indication of whether KM was happy for me to make a hot water bottle or not, she just said I could do it. The absence of negotiation and its associated emotional elements left me in spatial and social limbo. This resulted in my feeling disconnected from KM and the apartment, not knowing ‘how I was doing’ in relation to both. Was she happy with my demeanour in her space - I had no idea. When I visit my aunt, her expectations of my demeanour, are continually reinforced by the social cues evident in the layout of her house, its contents, through our dialogue and respective body language. These cues tell me where I can sit and how I must behave - the sofa and the Daily Mail.[24] This makes her and her space intelligible, creating a notional sense of acceptance and therefore comfort. Whereas KM’s space and demeanour provided minimal cues due to its bare white walls, lack of furniture and possessions. I had to create my own rules for using KM's space from previous experience, which told me my presence placed extra demands on her sensory and motor processing. However, it was difficult to judge the impact of my presence due to the absence of cues from her demeanour and our verbal interaction. This absence had a major impact on my spatial comfort in KM’s space.

I was not the only one to have this difficulty, a veterinary physician visited to inoculate May. He brought his assistant with him and I could sense that they were at a loss as to how to behave in the flat, if there had been furniture, there would have been conversation about where to sit and so on which would established the

[24] Conservative British newspaper

behaviour KM required of them. With few socio/spatial cues from the space and from KM to guide them, they took over the apartment. May fled to the bathroom where KM had personal items she did not want the vet to see. Before KM could stop them, the vet and his assistant followed and caught May. When the vet came out of the bathroom, he started making calls on his cell phone, which were nothing to do with his visit to KM, while his assistant inoculated May. When they left, I had the sense that KM felt invaded by their visit, saying she had not wanted them to go into the bathroom.

To me this incident illustrates that it is the demeanours that are absent as well as visible demeanours that challenge those who share space with autistics. Because KM could not signal through her space or presence the demeanours she expected her apartment was taken over by the vet and his assistant. I was also challenged by KM's lack of ‘phatic’ or reciprocal communication, which is conveyed through small talk, non-referential communication, used to establish a mood of sociability rather than to communicate information (Malinowski, 1989:315). In the case of my hot water bottle, KM communicated the information that I could make one, but did not convey sociability. This could be accounted for by KM's assertion that she relies on logic at Ben Shalom's level 3, so articulates agreement, but does not preconsciously integrate emotion, at level 2 to express social affinity (Ben Shalom and Clemerson, 2011; Grandin and Barron, 2005). Beadle and Blackburn also report issues with reciprocity, saying they use logic to shape their interactions with others (Beadle, 2011; Blackburn, 2011). Nazeer says that he and his friend Craig can only 'do argument' they cannot create or sustain affinity (Nazeer, 2006:128).

Van Ommeren et al suggest there is a gap in our knowledge of how differences in reciprocal demeanours manifest themselves in the daily lives of autistics and are experienced by those around them. They argue this is because criteria such as DSM-5 and ICD-10 use inaccurate definitions of reciprocity. Because of this they do not fully describe the subtleties of impaired reciprocity on daily interactions (WHO 1992 and APA 2000, quoted in van Ommeren et al., 2011:101). Van Ommeren et al suggest Gernsbacher's definition is more accurate:

'… a relation of mutual dependence or action or influence,' or 'a mode of exchange in which transactions take place between individuals who are symmetrically placed.' (Gernsbacher, 2009:139)

Inaccurate definitions, combined with the elusive, preconscious nature of reciprocity mean that it is difficult to locate live examples of autistics' differences in reciprocity in real life, unstructured interactions (Gernsbacher, 2009:140; van Ommeren et al., 2011:2001). This means we have limited understanding of how absence of reciprocity affects the spatial comfort of autistics and those sharing the space. We are presented with a contradiction, due to the intelligence and fluency with which many autistics speak, obscuring their issues in exhibiting sociability through reciprocity, resulting in them being judged as difficult or self-opinionated.

For instance, autistic speakers such as KM, IJ, Beadle, and Blackburn read and communicate with their audiences well. In many instances, those sharing space with autistics appreciate their articulate verbal presentation whilst being unaware, as I was, of their difficulties in meeting social expectations of typical reciprocity and therefore blaming autistics for shortcomings in sociability. Liebal et al argue this

contradiction in presentation, is obscured by most autistic children being attached and responding appropriately to their parents, and appearing to understand other people's intentions regarding actions in connection with objects (Liebal et al., 2008:225). Despite this appearance of connectedness, Baron-Cohen et al argue that 'typical' reciprocity, is difficult for autistics (Baron-Cohen et al., 1985). The ability to exhibit reciprocity is also complicated by sensory and other issues; in this case by KM's disunified vision, and because she finds focusing on eyes painful.

One of the strengths of this study is its illustration of how autistics' differences in reciprocity lead to socio-spatial limbo and alienation in both autistics and those they share space with, neither knowing how to overcome the impasse. This can lead to those around autistics to resort to scapegoating them for being different, judging, or blaming them for being 'difficult', leading to misunderstandings and social exclusion. To prevent this Gernsbacher says the wider population needs to develop its reciprocity purposefully and more generously in relation to autistics (Gernsbacher, 2009:142).

The layout of the apartment

To return to my narrative, I spent the rest of the afternoon sitting on a cushion on the floor writing up my notes and reading a book, whilst I was doing this I had time to absorb in my surroundings.

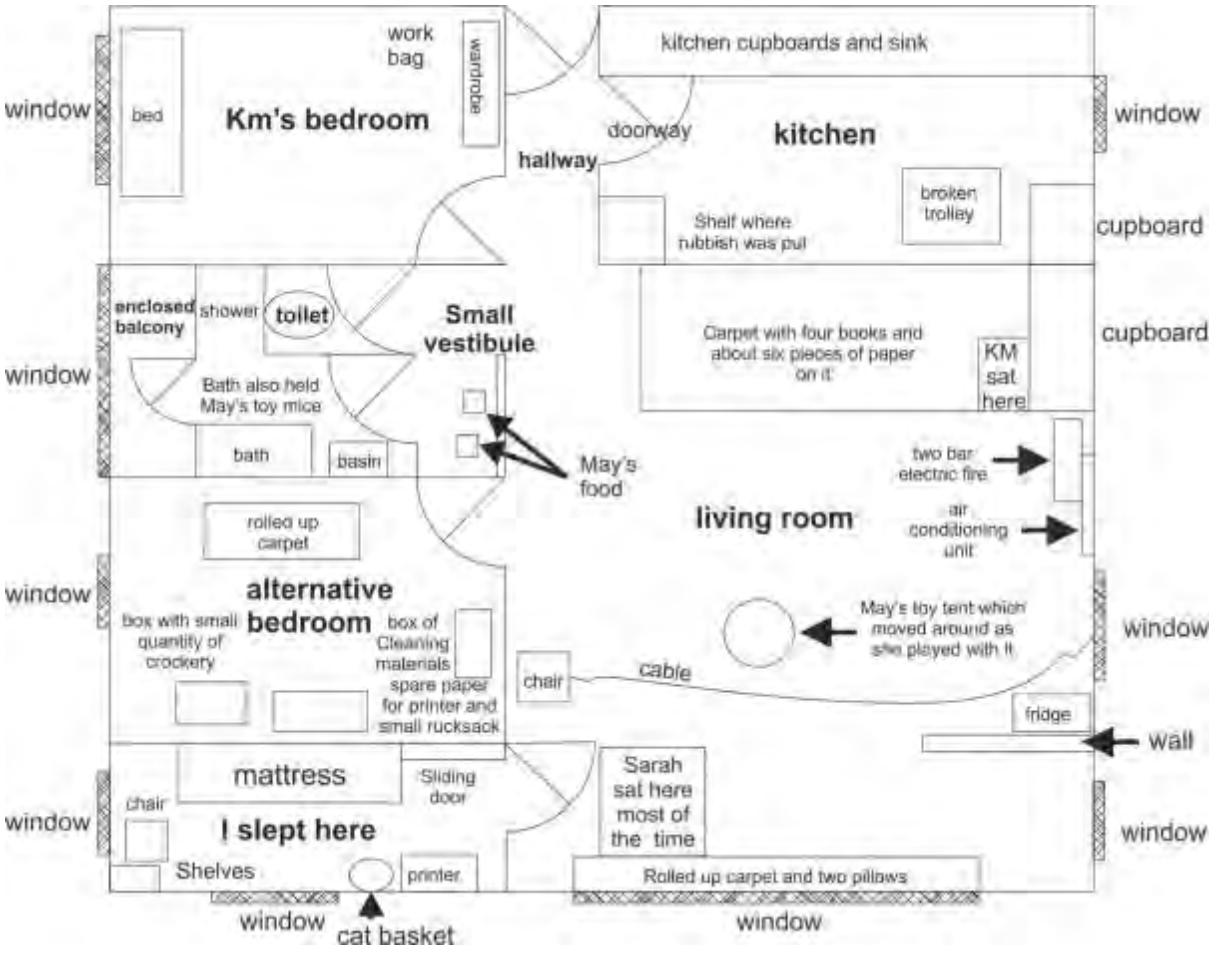

Figure 60. Indicative layout of KM's apartment

The walls of the apartment were white and the floor, grey terrazzo tiles. As I used the various rooms in the apartment, I discovered they were all nearly empty, including the cupboards, many of which were left open, to save the processing required to open and shut them. The kitchen cupboards, apart from a small cupboard, KM used as a larder were also empty. The fridge was in the living room, to save processing, KM rarely going in the kitchen. The fridge squeaked, catching on something every time I tried to open or close it. Later I realised it was because it was still standing on its original polystyrene packaging. I wondered why no one had removed it and considered offering to. Later, Km told it was there to fill in the gap between the

bottom of the fridge and the floor, as the gap was an additional thing to process every time she opened it.

The fridge was grubby, but not smelly. KM said her mother said she should clean it and the whole apartment before my visit, however, KM said she wanted me to see how she lived. Her crockery and cutlery, two plates, a spoon, a knife, and fork were kept on top of the fridge. When we had eaten, the dirty plates returned there, even things like skins of avocados. These were left until KM did her weekly house clean. This included disposing of her rubbish[25]. This mostly consisted of food containers. There were no newspapers, junk mail, sheets of old notes or other detritus, as KM uses a phone or computer to read or edit documents, rather than paper copies. The rubbish was kept unbagged on a high shelf in the kitchen, so May could not play with it; KM bagging it just before disposal. After KM had put out her rubbish, she did not clean the shelf to save processing. Cleaning the shelf is reserved for her once yearly spring clean. Despite this, the shelf was not that dirty and though May was using the bathroom as a toilet, the apartment did not smell, apart from the occasional smell of dried cat food.

KM has no cooker or microwave as she does not cook for herself, mostly eating ready-made food from containers to save the processing involved in cooking and washing up.

The living room contained a rolled up carpet, two pillows, one of which I was sitting on, a chair; a hessian rug that was spread out, which had four books and some

[25] trash

sheets of paper on it; a two bar electric fire and an air conditioning unit. KM sat on the hessian carpet to the left of the electric fire most of the time when she was in the living room. The room also contained a mini pop up tent, a freebee from a cat food manufacturer that May frequently played in, rolling around in it on the floor. When May had finished playing, it stayed where she had left it. Even on one occasion when the tent had already knocked May's water over and was in danger of doing so again. The bags containing May's food were placed on the floor in the vestibule next to the bathroom. These bags and May's and KM's other few possessions did not noticeably move position, despite their apparently random placement throughout my stay.

I discovered the back wall of the middle bedroom was cream after a few days, which made it a more comfortable space if you looked hard enough. However, it was still dark in there as the shutters were closed all the time and the apparently randomly placed objects did little to unify the space. The shutters were closed because the climate KM's country is normally very hot, although I visited in winter when it was cold and wet. I felt cold during most of my visit and was glad of my hot water bottle and the kettle provided by KM's mother.

The bathroom and toilet were grim, the floor, walls, and sanitary ware stained due to age rather than dirt. There were two drains in the bathroom, dark holes with no covers, as May was expert at removing them, meaning KM had to get her father to put them back. I was unnerved and felt slightly sick when I heard that May used the drains in the bathroom as a toilet. KM said taking out the cat litter would be too difficult.

KM kept May's toy mice in the bath so she did not trip over them. During my stay, May got into the food cupboard and stole the netting off the fruit to play with. KM put

this in the bath as well, showing me how having a red mouse at one end of the bath and the red netting at the other balanced the bath visually. She said had one red been a blue red (cool red) and the other a brown red (warm red) that would have caused visual pain.[26]

KM said everything in her apartment has a purpose and value. She likes her possessions to be spaced out, so she can see clearly where things are, making clear routes around the objects so she can move between them without thinking, to save processing power.

Computing energy requirements

As KM and I discussed the previous section, I realised KM's organisation of her space is determined by the need to reduce the impact on her processing in addition to her senses. A colleague of KM described her as being like a kernel in a computer. The kernel being the name for the core processing function within an operating system for instance Unix/Linux. UNIX acts as the brain (kernel) of the LINUX operating system, mediating between the computer's hardware and its applications to schedule what needs doing (The Linux Information Project, 2005). The kernel's processes are definable whereas many of those of the human brain are preconscious, depending on 'educated guesses' for interconnections between different parts of the brain (O'Shea, 2005:64). However, even though the kernel's process are definable, it can only do them in terms of its rules. If the rules are infringed, for instance a process is given a low priority, and is then interrupted or

[26] Figure 26 in Section 1 of this chapter illustrates the difference between warm and cool colours

there are too many processes running then it may be that certain individual processes almost never run (Walker, 2012).

Hence KM's preoccupation with her processing, not just because preconscious processing is almost absent (level 2), but because although like the computer she relies on logic (level 3), this is not always reliable due to the nuances of space. Also, consider the example of my computer, which at present has 73 processes working simultaneously for only 10 open applications. As KM's processing is not preconscious, she similarly consciously attempts to balance many physiological, emotional, and social processes to manage space on all levels.

Sinclair makes a similar comparison, referring to his processing as being like a computer, 'frantically' attempting to share and prioritise processing requirements between applications (Sinclair, n.d.-b) A review of research developments in autism carried out by Minshew and Williams state that autism has a broad impact on cognitive and neurological functioning. They argue this places high demands on the integration of information and coordination of multiple neural systems in high-functioning autistics (Minshew and Williams, 2007:945).

KM says her processing takes over her life 'everything is there and keeps being there'. For instance, the motor planning required for the pronunciation of 'good morning' instead of 'hi', 'almost kills her'. KM says 'hi' is not acceptable in her professional role, the pressure being to do 'exactly the right thing', or be sidelined. Reed and McIntosh describe this type of interaction as a 'dance' which requires huge amounts of processing of the intentional relations of self and other (Reed and McIntosh, 2008:83). Because of these demands, KM avoids change to prevent the

additional processing it creates. Not understanding the effect of the absence of preconscious processing in KM's personal and spatial management and her compensations for this could lead to her being stereotyped as inflexible.

Episodic memory and the organisation of space

When we were discussing her apartment, KM told me she had another one that she rented out. She said she had bought that apartment ready furnished as she thought it would take her ten years to furnish it if she had to do it. KM said it was both difficult for her to travel to Ikea and to get the furniture home. However, more importantly she could not imagine how the furniture she saw would look in her home, due to the absence of episodic memory. Lack of episodic memory affects future thinking, meaning KM cannot visualise what the new furniture would look like in her apartment. The result is that she has lived in the current apartment for a year and only bought a carpet, which is rolled up in the living room and two cushions.

The effect of KM's space on me

The absence of all but the most basic spatial and social cues and KM's hyperarousal led me to also be hyperaroused, which meant I had difficulty in sleeping, appearing only to sleep for a couple of hours on the second night. Part of this was because I had to wake at four-thirty so we could leave at five-thirty am to catch the train to KM's workplace. I was worried whether my alarm clock would work, if my cards would function in the ATMs, and whether I would find a toilet if I needed one. I knew I was being illogical and was trying to reassure myself. Especially when I found on my return from the supermarket that I did after all have cash with me. It was in my passport, which I do not normally carry with me when I am abroad in case it is stolen, but which I had been advised to keep with me.

Altercations

Twice during my stay with KM, we had a minor altercation. The first was after we had arrived home after KM's day at work. KM had arranged for one of her colleagues to show me the tourist attractions the next day. I had to catch a bus to meet him and said I would go for a walk to make sure I could find the bus stop. Without thinking I said I would be half an hour or so, but not knowing the town I was away about an hour. When I got back, KM was furious, part of me went to paternalistic, 'tick box mode', 'always avoid ambiguity when dealing with autistics' and felt deskilled. KM said she had wanted to sleep, but had stayed up to let me in as I had said I would only be half an hour. From feeling carefree and happy after my walk, the feeling of doom returned from the previous day. I had found somewhere to buy sushi, which I knew KM liked, and had menus so she could choose what she wanted, and was going to return to collect it. However, the emotional effect of KM's justifiable criticism left me silent and unable to share the menus, she went to bed, and I did not see her until the next day. On the other occasion, we returned late at night after a long bus journey. As we approached the apartment, KM said that May would have missed her, and that when she went into the apartment KM would pick her up, and needed a few minutes to comfort her. She explained that May sometimes struggles and KM was worried that her claws would rip her jacket, but if I was quiet, we could avoid this. I was tired and carefully followed behind KM, concentrating more on not letting May out of the apartment. KM picked her up and stroked her and I walked across the room. I got to the door of my room and disaster, without thinking, I pulled the door open, the bottom scraped the floor, making a noise due to its dropped hinges. As if that was not bad enough, almost simultaneously I trod on the one loose tile in the floor that happened to be in the doorway. This frightened May who struggled,

scratching KM’s eyelid and her jacket. KM was angry, but not shouting. She said the equivalent of I told you not to frighten May but you disobeyed me. My emotional reaction to her tone was that she thought I had deliberately frightened May, whereas it was a complete accident. Being in unfamiliar surroundings, I was not instinctively aware that to avoid making a noise I should not move the door and needed to avoid the tile. My priority had been not to let May out of the apartment, to get through my bedtime routine and go to bed.

I realised on reflection, that KM's emotional reaction to both incidents was not modulated at Ben Shalom’s level 2 (Ben Shalom, 2009:589). I felt under attack, feeling her criticisms were largely right, but that her reaction was out of all proportion to what I had done. I had not meant to make a noise, in the same way as the day before I had not meant to inconvenience her by taking longer than I had said. I felt deskilled and stupid because on each occasion I had not picked up or more importantly acted on crucial aspects of KM's communication, regarding the rules of her space. This is especially so as I know from my experience as a support worker, that autistics rules or requirements are often unwittingly or intentionally breached.

Despite this awareness, my emotions were tinged with a feeling of unfairness and a wish to resort to labelling KM as controlling. However, after similar experiences recounted in Section 1 in the account of the journey, I realised this was not so, so I said sorry and continued to bed.

When KM is angry, I always find it difficult to respond, firstly because of the emotional effect it has on me, and secondly because her arousal signals to me that it is better to say sorry and leave it, rather than escalate the disagreement by

argument. The next day KM was sorry, although she did not explicitly say this. She said she had told her mother what had happened, and her mother had said ‘she should not be horrible to me’. I feel sure her mother did not put it that bluntly, but when KM talks about emotion, she expresses the extremes of horrible/nice rather than the nuances in between.

One of the main reasons for recounting these incidents and the data from my stay with KM is to examine the impact of her space on me. Often when people discuss disability and space, the focus is on disabled people, viewing spatial issues as something specific to them rather than something that affects everyone. However, anyone put in an unfamiliar situation will feel many of the same things as an autistic person in a similar situation, and react in similar ways. For instance, I was hyperaroused and was convinced I had no money with me in the supermarket, when I did. I was also clumsy and noisy, I did not know the rules, and could not read the social and spatial cues of KM’s space and demeanour, which is similar to the predicament of many autistics even in spaces they have visited many times before. For many this is due to lack of integration of preconscious processing at Ben Shalom's level 2 leading to differences in episodic memory, reciprocity and emotional regulation for instance (Ben Shalom, 2009:589).

The station

To return to my narrative, the next day we returned through the park to the train station. When we arrived, KM suggested I used my card to get a ticket, as the machine only requires the card to be swiped, and would be an indication of whether my card would work in the ATMs. To my relief it worked and after that, I had no further problems with my cards, on cue there was also a public toilet. My use of

these two simple spatial elements left me happy and content, set up, ready for the day.

Bumping into people

As we approached the ticket barrier, three young men came in the opposite direction. KM abruptly pulled me out of the way and said quietly ‘they are like puppies, they mean no harm, but they will bump into you’. I was put out by being unceremoniously pulled out of the way, when the young men had not even reached us. I felt I could have got out of their way, or used body language to tell them to go round me/us or at least make space for us to pass each other.

I later connected this with my observations of KM bumping into people as we walked along the various platforms and on the trains. I also observed KM's attempts to try to avoid this, for instance, when we were standing next to a luggage rack, and someone went to get their case. KM attempted to move out of the way, ending up even more in the way, this happened several times during my visit. One example that disturbed me, as I was afraid KM would be hurt, was when we walked along an apparently deserted platform; suddenly more people appeared and started overtaking us. Two young men overtook me separating me from KM, walking quickly behind her; they were talking and gesticulating animatedly. They were tall and gangly, whereas KM is small and slightly built. I was quickly aware the two men and KM were unaware of each other. When KM did become aware of them, they were almost walking into her, talking, and gesticulating, still not registering her presence, one of them nearly elbowing her in the face. KM was unable to get out of their way. The men remained unaware of her presence and continued walking and talking.

This illustrates the practical nature of KM's rule to ‘keep out of peoples’ way and in particular of young men. When we discussed the incident later she said, ‘it happens all the time.’ KM said 'when things get really bad' she puts both hands together like an arrow in front of her to get people to understand where she needs to go. I first thought that KM bumped into people because she could not process the environment fast enough to move out of their way or to assert herself in space due to her assertion that she has a lack of body awareness and sense of self.

When KM and I discussed the incident on the platform, she said this was partly right. She explained that it takes 30% of her processing to walk with me and 60% if we are walking and talking. In my previous research employing ethnodrama, I found it extremely difficult to navigate space and talk with reduced sensory awareness (Clemerson, 2011:45). Geneva, provides a graphic description of difficulties caused by having to balance processing using conscious thought and perception in a similar way to KM and the stress it causes:

People don’t realize the major problem that nobody ever sees or realizes is how much conscious thinking we have to do just to function. Walking takes thinking. So if I am walking and you ask me a question I could trip or I could mess up the sentence and put the wrong word in. Or have to stop and say what did you say? I can walk with my girlfriend down the street and carry on a conversation as long as she is right there but I have to look down at the sidewalk. I have to keep track of where the sidewalk is and where any obstacles are and all that stuff and sometimes if I have to keep walking and I feel like I am going to blow any second I make sure the path is

clear ahead of me and close my eyes and continue walking (quoted in Strandt-Conroy, 1999:124).

Belmonte et al and Minshew et al in their discussion of autistics' impaired ability to rapidly co-ordinate actions, suggesting that this is due to impaired connectivity in the brain. Historically accounts of impaired connectivity are focused on white matter, but more recent functional magnetic resonance imaging activation suggests that intracortical connectivity may also be disturbed (Belmonte et al., 2004a:646; Minshew and Williams, 2007:945). Castelli et al found in their research that autistics were less able to read interactive movement with implied intentions than typically developing people. They suggest this is due to a bottleneck in the interaction between higher-order and lower order perceptual processes (Castelli et al., 2002:1839).

Body awareness and movement

KM told me that she has limited awareness of her body. I was at a loss to understand what this might equate to when using space, so I carried out a mini experiment in King's Cross Station, London. I used drama improvisation to think myself into having no awareness of my body. I then walked against the flow of people arriving at the station twice. When I walked without consciousness of my body, I suddenly saw everything at once, faces, and eyes coming at me, all seeming to be looking at me. This is in sharp contrast to other occasions where I have walked against the crowd, focusing my mind and body, moving through people in a straight line, like an arrow. Reflecting on this, I normally use conscious awareness at level 3

to tell me how to walk from A to B through a crowd, in conjunction with my preconscious processing at level 2. Using level 2, I integrate the information from the crowd to adjust my bodily movements and demeanour intuitively, to get the crowd to let me pass or risk me bumping into them. When I recounted this experience to Ben Shalom, she said that I had suspended my preconscious processing at level 2, and therefore was seeing 'everything' in its raw, unintegrated state at level 1 (Ben Shalom, 2011a). This meant I saw everyone and everything at the same time, including swirling bodies and objects in my peripheral vision. Those looking at me were probably trying to work out where I was going, as having suspended my bodily awareness I did not know, and therefore could not signal where I was going to move next. I had to stop after 30 seconds or so, not because I was worried about bumping into people but because the experience was so dramatic and intense on both occasions.

Mukhopadhyay describes similar experiences, stating that he sees himself as a spirit rather than a body. He feels that his body is scattered and difficult to gather together, so he uses spinning as a stimulatory behaviour to unify his body parts (Mukhopadhyay, 2000:20).

Travel preference - KM's preference for public transport

I will now move away from a strictly chronological account of my stay with KM to look at the way she travels. Firstly, she travels as little as possible, mainly working from home as travelling to work requires a two-hour train journey. KM prefers walking, trains and buses to taxis or being driven by her family, which exasperates them as the journeys would take less time. Even when navigating her way through the main

bus terminal, filled with chaotic shop fronts, light, noise, and reflection, KM has a route that takes her straight to the lift and her platform, avoiding virtually all the visual clutter and noise. As I accompanied KM, I began to understand her preference for buses and trains. I realised in a similar way to KM's preference for using ticket machines, discussed in the previous section, KM can use a computer to get train and bus times, to avoid the unknown 'variables' of social interaction, involved in getting a lift[27] from her family or using a taxi. In addition, buses and trains run at certain times on prescribed routes that rarely change and they stop at the same places every time. As KM does not need to interact, on trains in particular, she can sleep during the journey saving processing power. If she accepted a ride from her family, KM would firstly have to negotiate this, which always seemed to cause conflict. For instance, when we planned to go to a restaurant, KM's mother gave me a message to ask KM to let her know the evening before if we wanted a ride, as she would have to fit us in before her class. I relayed the message, but KM only rang the next day, ten minutes before we wanted to leave. This resulted in an acrimonious conversation between KM and her mother; I think not ringing had more to do with episodic memory, planning and exhaustion rather than being intentionally difficult, which I think is often how it is perceived. Getting a ride also meant KM would have to engage socially during the ride 'costing' processing power.

Buses

Buses could still be problematic for KM, firstly because the drivers could never understand why she sat at the back of the bus when she was disabled instead of

[27] ride

sitting near the door. However, the drivers all had their radios on, so KM sat at the back to avoid the noise. Secondly, sometimes confusion caused by passengers ringing the bell for the wrong stop means the driver ignores the bell for a legitimate stop, resulting in KM having to shout at him to stop.

Taxis

Taxis are also problematic for KM because, ‘there are many unpredictable variables, for instance, those involved in negotiating the journey, its route and where it stops. Even after this KM may have little control over which side of the road, or which entrance of a building the taxi will stop at, or how long the journey will take. This is further complicated because the language of many of the taxi drivers is not KM's first language or English and similarly they come from different cultures. All these aspects cause KM considerable extra processing, hence her liking for the predictability of buses and trains.

At work: KM’s office

As well as travelling with KM, I also accompanied her to work. Her office as her home, contains few possessions in comparison to her colleague next door, whose office contains all the accumulation of someone who has made the space their own. While KMs’ office after a year of occupation still has nearly everything in boxes. She said if people commented she would say she had just moved office.

Lighting

KM pointed out the fluorescent lighting in her office, which she only uses if colleagues insist; otherwise, she uses an uplighting, halogen lamp, which provides softer lighting. KM does most of her work in central work areas with fluorescent lighting. KM says this is not too bad if the lights are new as they give off the same

light and flicker rate. However, in rooms where the fluorescent tubes have been replaced their flicker rate and light colour vary, due to age, making them painful to process. At home, KM only used the lights in her living room when I arrived; from then on, she relied on the light from the two bar electric fire. Having no light in my room, I lit the light near the door to dress and undress by. KM finds daylight too bright, keeping her shutters closed even in winter.

Fluorescent lighting is well known to be problematic for autistic peoples' spatial comfort. Fenton and Penney illustrate its role in instigating repetitive behaviours (Fenton and Penney, 1985). A more recent study by Winterbottom and Wilkins found that typically developing children[28] were particularly sensitive to fluorescent lighting and glare in learning spaces (Winterbottom and Wilkins, 2009). Even well maintained fluorescent lights flicker due to the electric current changing phase 100 (Europe) - 120 (North America) times each second. Protigal suggests this is because fluorescent lights rely on ultraviolet light being 'fluoresced' down to visible light frequencies. However, he argues this spectral light output is not continuous, forming a series of spikes that cause the pupil of the eye to alternately dilate and contract. Protigal suggests it does this in response to red and blue spectral peaks in light that cause the pupils of the eye to erratically adjust or flutter. This is perceived as flickering, causing neurological discomfort in the form of headaches and fatigue to many autistics and others (Protigal, 2011). OP in Chapter 3, as does Protigal, argues that 'online' flicker is reduced if fluorescents are fitted with electronic ballasts, which

[28] I assume that the children involved in his study were the general school population, which may have included autistic children who attend mainstream school.

also reduce running costs, and spatial discomfort. Compact fluorescent lights, the spiral bulbs used to replace incandescent bulbs do not eliminate flicker for many people. Protigal argues that many autistics cannot tolerate these or any kind of fluorescent lighting.

At work – attending a meeting

I attended one of KM's meetings, its subject was not one I was familiar with, but KM appeared relaxed, fluent, and animated. There was a problem with the technical equipment, but KM quickly got her colleagues on board to get it up and running. Those attending the meeting were also animated and everyone including KM was fully engaged in the discussion.

Hyperarousal

However, once the meeting was over KM appeared to return to her hyperaroused state. On reading this, KM said my assumption was wrong. She said she was hyperaroused throughout the meeting, describing her state as equivalent to that of an athlete, who prefers to be more aroused than is comfortable to enhance their performance.

As we walked, back to the office, KM said she lives in present. She says she perpetually feels fear, but not anxiety as this requires forward thinking, which she says she cannot do, having no episodic memory. KM says she plans, but does not ‘experience’ the future when planning it, so is not scared by it, only by the present. KM said her perpetual state of fear means that she likes to have only the possessions she can carry, so that she can ‘run’ or escape more easily if she has to. KM said when she was younger; if she was sensorially overwhelmed or about to

collapse she would run away. She told me that she felt like a trapped animal most of the time. When we got back to the office, KM checked her email and then put three of the office chairs together and went to sleep for the lunch hour. To give KM privacy and quiet I went outside, eating my lunch in a nearby seating area.

Hyperarousal versus fear

I have referred many times to KM's hyperarousal and its effect on her spatial comfort in the preceding sections, on reflection using the word uncritically. A definition of hyperarousal says it is a state of increased physiological and psychological tension (Wallhausser-Franke et al., 2012:4f).

The effects of hyperarousal are discussed in autistic authored writing, as well as by KM and other autistics I have met during this research (Gerland, 1997; Grandin and Scariano, 2005:27; Williams, 1992:45). KM distinguishes between fear and anxiety as do Grandin, and Ben Shalom, all agreeing that fear is ‘if you tread on a snake, whereas anxiety is when you think about treading on one’ (Faran and Ben Shalom, 2008:90; Grandin and Johnson, 2005:191).

Fear and fight or flight reactions are an important part of our evolutionary survival, laid down in the primitive cortex of the brain (Lang et al., 2000:138). However, in the case of many autistics the associated physiological and psychological reactions are not modulated, if we follow Ben Shalom’s argument, through integration at level 2.

Most of the literature on fear/hyperarousal discusses its effects, for instance autistic behaviours that challenge society not the experience of the person undergoing these emotions (Goodwin et al., 2006:100). This means there is a gap in academic writing

regarding the lived experience of fear and anxiety in relation to autism. Green and Ben-Sasson's conclusion that anxiety and sensory issues feed each other is supportive of many autistics' experience (Green and Ben-Sasson, 2010:1495)

Grandin argues that typically developing people mediate fear through humour, empathy, and thought mixed with altruism, or intellectualization (Grandin and Johnson, 2005:91). KM cannot integrate these feelings so she intellectualises them using logic at Ben Shalom's level 3.

Noise

KM's apartment was surprisingly quiet, with little noise from the road or the park it backed on to. However, there was a fair amount of noise from the apartment above, appearing to come mostly from the residents moving furniture. KM said this type of noise was not painful but voices and music are. The uncarpeted stairs outside the apartment are also a source of noise, from footsteps and people talking. KM has a thin front door, and this together with the lack of soft furnishing means that noise from the stairs echoes around the apartment. KM said she could manage the noise from the stairs once or twice a day. However, she did complain about the noise of birds in the trees outside that wake her at dawn. She said that in her other apartment she was on the sixth floor so the birds did not wake her. OP also complains about birds waking him at 6.00pm, as well noise from the elderly woman who lives above him. Nazeer describes birdsong as noise with content even though it is not human noise, he would prefer the sound of traffic (Nazeer, 2006:99).

KM describes two types of noise, noise with content and noise without. For her noise with content is that of people talking and from music which she finds extremely

uncomfortable and distracting. Certain types of music have this effect on her despite her being a singer and musician. For KM, noise without content consists of repetitive noises like the hammer drills used in road building and construction, which KM says she can sleep through happily.

Chapter 5: Those with severe issues with executive function

In this chapter, the body of the narrative of our go-alongs is written directly on the page and the participants' and my commentary and analysis is in the grey boxes, so it is important you read them.

The narrative shows clearly how I made inaccurate assumptions when sharing their space. Within the grey boxes I explain how, based on their demeanour and the appearance of their homes, assumptions were made. These accounts are then triangulated with autistic authored and academic writing.

IJ	Mid fifties, parent, activist, trainer	Type II
MN	Late forties, parent	Fewer sensory issues, but more severe social issues, severe issues with executive function

This chapter explores the socio/spatial experiences of IJ and MN, who fit into Type II of Ben Shalom's Typology. They are included in this study, because they chose to be, considering their spatial experience important in informing others about autistics' spatial requirements. They both face severe consequences, IJ who is alienated from her community and MN who is homeless. In both cases, their spatial concerns largely involve others' perceptions of their homes and demeanour in them.

Together with KM, they had considerable input, coming the nearest to fitting the category of co-researchers. This was due to our intense negotiation of the hyphen to understand each other's perspectives. I 'went along' to IJ and MN's homes, the space causing them the most concern; although home for MN was at first a room in

her lodgings, and then for the last two years of this study, emergency accommodation in a hostel.

For IJ and MN, it is the ideological and contextual elements of social and interactional space, within their homes that is problematic, compounded by their homes becoming the workspaces of support workers and thereby semi-public.

This chapter shows how autistics' space and their demeanour in it can threaten the membership of support workers' reference groups, due IJ and MN's homes becoming their workspaces (Shibutani, 1955:564). This means autistics' homes and their demeanour in them comes to reflect the support services effectiveness or not. My intention is that by reading my initial impressions of IJ and MN's spaces and demeanour, followed by their accounts; the reader will be shown how this led to inaccurate assumptions being made about them. This affects the spatial comfort of the participants' homes and their functioning in interactional space, affecting their access to appropriate services.

Section 1: IJ: a case of not being able to control your own space

IJ	Mid fifties, parent, activist, trainer	Type II Fewer sensory issues, but more severe social issues, severe issues with executive function

IJ is an autistic woman who lives in a maisonette on the ground floor of a seventies style high-rise, publically owned, housing scheme. MN is also autistic living in one room, in emergency hostel accommodation, where one of her children also has a room. Both women are sensitive to noise and social stimulation, but do not report the extreme sensory issues of KM, although MN also has issues with balance and visual integration. I describe my visits to both women and my response to them and their homes in some detail, to illustrate how the appearance of a person's space and their demeanour leads to negative assumptions about them and their lifestyle.

My first visit began by going down a narrow outdoor walkway to IJ's maisonette; the dirty windowsills and grubby net curtains give the space an abandoned, forbidding feel. This was not helped by a high bank of unkempt grass and shrubbery opposite; reaching to the floor above's walkway, keeping the ground floor in shadow. There was a large upholstered footstool outside the maisonette, where I later discovered IJ and her friend sat when they were smoking cannabis. I knocked on the door and was invited in. IJ invited me to make a cup of tea while she finished talking to her support worker.

I was instantly visually bombarded by the objects in the maisonette, which reached from floor to ceiling; some on shelves, some piled shoulder high on the floor. I was immediately disorientated; the usual cues signalling where to go and the function of the different rooms were not there. I felt I was experiencing something similar to KM, who sees everything, but cannot intuitively filter it. Here, as in KM's apartment, I could not filter the socio/spatial cues from the space and the arrangement of objects in it, to orientate myself. In KM's apartment, there were not enough spatial cues and in IJ's there were too many, not helped by the kitchen being on the next level down. I did not have a clue where to go, and then I saw a narrow path going in the opposite direction to IJ so I followed this although I had no clue where it led.

As I tried to find the kitchen and somewhere to sit, I discovered other rooms full of objects. I walked through 'a sort of hall area' and then down some stairs, which led to the kitchen. Here the mixture of objects and the smell of cat's urine overwhelmed me (IJ's home did not always smell of cat's urine). Every surface was covered in objects, a narrow path leading to other rooms, whose purpose was not apparent, but where I hoped I might find somewhere to sit. However, these rooms were also piled with objects, including rabbit food and bedding, building materials, and parts of flat pack furniture. There was nowhere to sit, the one chair I saw in the kitchen was covered in stuff, but there was nowhere to put it, if I tried to move it. I felt helpless and not inclined to move anything, feeling out of place and somewhat disgruntled after a long journey.

As I began to make sense of the space, the kitchen's apparent dissonance with the rest of maisonette became apparent. It had the paraphernalia of an upper class 'Homes and Gardens', country kitchen, complete with kitchen range and stone floor.

Where it digressed from this was the objects had taken over the space, including the top and underneath the kitchen table, leaving a narrow path, to the rest of the maisonette. At first, the kitchen appeared dirty, not helped by the strong smell of cat urine, dirty counters, and the stainless steel sink lined with a coating of congealed, fat and tea. However, my perception needs to be viewed in the light of my past experience as a hospital cleaner, plus my low tolerance of clutter; a response to a mother who never threw anything out.

As I became used to my surroundings, I realised the disorganised appearance of the maisonette made it look ‘dirtier’ than it was. Closer inspection revealed the arrangement of objects on the walls was colourful, aesthetically pleasing, and probably no dustier, than those in my home. My initial judgement from my perspective as a support worker was IJ’s workers should have supported IJ to keep the kitchen cleaner or have done it themselves to create a moderate sense of order and hygiene until IJ could manage these tasks for herself.

Eventually IJ was free and called me. It was hard to tell where I was in the maisonette in relation to IJ. The maisonette was like a warren. I found IJ near the door I had come in by and we went into her bedroom, which was the length of her bed wide. The bed was on a platform, one meter from the floor. IJ said she liked to be up high when she slept, showing me the panoramic view of the city through her window. IJ said she would be miserable in a low bed, it being important for her well-being to have sunlight on her face in the morning, something her occupational therapist would not take into account. IJ has fluctuating mobility due to arthritis.

In the bedroom every available surface was covered with objects or clothing. This just left room for a computer table, the two chairs we were sitting in, a path to get into

the room and to the bed. I took several minutes to make sense of my surroundings, when I did, I saw the objects were in good condition, interesting, colourful and mostly tastefully arranged, despite their overwhelming number. Many were on shelves, divided into foot square compartments covering many of the walls. I became mesmerised by a group of shelves filled with T-shirts that had not even been removed from their plastic bags; wondering at the money they must have cost and the space they took up.

I felt frustrated by IJ and her space. It took me a long time to understand why she did not prioritise jobs.[29] I accepted she may be tired and in pain, making it impossible to clear even part of a room at a time. But, why could she not breakdown the task to just remove the items she knew she did not want, leaving room to sort the things she was not sure about keeping? Such was my frustration, I even dared suggesting taking a few trays of food to one of the many local charities each day in her car, or getting them to come and collect it. However, this seemed a sensitive topic so I left it. IJ later made a computer room out of her ex-lodger's room, subsequently turning it into a very tasteful guestroom, but despite this the rest of the maisonette remained disorganised.

Cannabis use

During my visits, I gradually became aware IJ and her friends were using cannabis, which for some reason I rarely smell. I can sit next to someone with a gigantic spliff

[29] An autism professional may have immediately known why. However, in this study it is important to illustrate my process to understand others' reactions in similar situations, and how this affects autistic's spatial comfort.

and still not smell it.[30] They smoked outside the front door, IJ sitting on the large footstool, the neighbour complaining his children could smell it if they smoked in the maisonette. IJ did not say why she used cannabis but I assumed it was because both she and her friend had very painful arthritis. While they were doing this, I took in what was happening, somewhat in a state of culture shock, despite my experience as a social worker and knowing the purpose of the drug was at least partially therapeutic. I felt left out, frustrated and judgemental about their lifestyle. I missed the articulate and challenging conversations I had with participants such as KM and OP and wondered what data I would get. IJ's demeanour and experience seemed very different to the other participants, apart from MM. I began to assume that IJ, a middle class, university graduate, had chosen an alternative lifestyle, including living on benefit. This was not helped by IJ describing herself ironically, as a ‘refugee from the middleclass’ and her friend also being on benefit.

A case of assumption by appearance and lifestyle

I made more judgements; IJ seemed able, and articulate. I think if she had just been on unemployment benefit or had not been claiming to be autistic, it would not have worried me so much. As it was, I quickly viewed IJ and her friends as an undisciplined, demanding group of 'new age hippies' who were taking advantage of the social security system. My punitive judgements were compounded by the presence of IJ’s support workers who provided meals and drinks, with no input from IJ. As a support worker, I always prepare meals with, rather than for people, which raised issues for me about privately funded care. A support worker has no incentive

[30] Before this study, I was of the opinion cannabis should be legalised, but over time seeing how one of IJ friends struggled to come off it, I think the situation is more complex.

to encourage someone to do things for themself, if they think it will interfere with their continuing employment or to challenge a client who may become volatile. Making a meal can be satisfying and grounding.

My initial judgement was having such a crowded space indicated distress, but I was not sure it was due to autism. I perceive myself as not making judgements about people being on income support or unemployed. However, receipt of disability living allowance and having support workers made me judgemental. Instead, I uncritically perceived what I thought at the time were mental health and mobility issues that could be helped by organisation, diet, and exercise. I judged as IJ was so articulate she got benefits and support where others could not. However, IJ said later she had fought hard to get benefits to survive and not because she felt entitled to them.

As before, IJ's account and our reflections are in grey boxes to distinguish them from the narrative.

IJ's lifestyle, superficially at least IJ did not meet my expectations of an autistic person. I now present IJ's account of her space and the issues it presents her with and debunk my assumptions topic by topic.

IJ's account: her organisation of space

IJ says the layout of space is important to her, and it is important for each person to have their own room. IJ said she liked to have many rooms each having a different function, eventually hoping to have a sensory room, a conservatory, a study, and a sitting room. IJ had gone some way towards this, following her 'imperative to get rid of the walls and extraneous things'. This meant using her skills as a professional

painter and decorator to remove nearly all of the non-supporting, internal walls to create the maze of small rooms I had encountered.

IJ's relationship with space: a case of alienation from her own surroundings

IJ says she finds her own space 'deeply distressing', one of her daughters refuses to visit and the other rarely does. Her distress was particularly acute when I first visited, as she had three lodgers, who made her feel even more out of control of her space than usual. She said they accidentally broke things and did not put them back in the right place. IJ said if things were not in the right place, it felt like a physical illness. She said the perception of her home as dirty and untidy, meant others viewed her space as a 'wreck', leading to them abusing it. IJ said one of the reasons for her home's disorganisation was she had had no support to unpack from her move to her maisonette twelve years ago. IJ said she wanted to get rid of many of the things in the maisonette, but these were interspersed with precious items such as some of her children's artwork and her own childhood toys.

Without clutter IJ says she feels secure, but at the moment is at a loss to know how to organise herself to remove it. She finds others' judgements about her space and attempts to help her counter-productive for reasons which we discuss below. She said over buying of clothes and food was a result of 'days of anxiety'. IJ said she had bulk bought T-shirts intending to tie-die them to sell at festivals, but had been unable to do this. IJ said she was not sure if it was the arrangement of her space that prevented her doing things or having to 'figure out each object' and then think where everything will fit. She said she had wanted to get the space right for her children,

but had been unable to do it and they were now adult. IJ said she had had support to reorganise her bedroom from a previous support worker, but they moved on before it was finished, stalling the reorganisation for three years. A major issue for both IJ and MN was a lack of continuity of support workers.

A case of inertia and monotropism and its effect on the organisation of space

The second time I visited IJ was a month after her lodgers had left. The larger of the rooms they had occupied became IJ's computer room. It was filled with second-hand, flat pack furniture, an occupied rabbit hutch, a double bed standing on end against the wall, leaving just enough room for IJ's chair and computer table. IJ said the room was 'too full of wrong things'; she gets trapped into 'potholes' like Facebook and food websites, and is unable to switch to other activities, even when bored to death by the computer. Grandin also says she can become mesmerised by screensavers (Grandin and Barron, 2005:). This is compounded by mobility issues, making it exhausting and painful for her to move out of her chair, making her reluctant to leave the computer as she may not be able to get online again until the next day.

Not being able to switch activity leads to IJ being accused of laziness and procrastination. IJ says her fixation on certain tasks, gives the impression this is something she decides to do, rather than something she cannot control. Switching task is not such a problem if her support workers are present. IJ says having someone around breaks the spell, even the dog coming to stare; although IJ says it takes ages to work out he is hungry. IJ said when she looks at her space, she can

partially sequence what needs to be done, but she cannot do it, which is ‘torture’. She said sometimes she can sit waiting to do something, but being unable to do it; sometimes rocking all day. At other times IJ said she could sit waiting to go to the toilet so long, she was nearly bursting, because there was no prompt from the environment to tell her to go. She said sometimes her animals, a dog and two cats, prompted her to do things, Sinclair discusses the role of service dogs in his story of his dog Isoceles (Sinclair, n.d.-a). At other times, she would keep rearranging the same things, for instance one day, seven containers of cereal and beans. IJ said she loves to line things up and fit them into small spaces. She said she tried to arrange the tins in the colours of rainbows, turning them so the bar codes do not show. This fascination means sometimes when IJ is in a supermarket she can become fixated on certain items, for instance spending up to an hour calculating which paper notebook is most aesthetically pleasing and best value for money.

A case of ambiguous appearance and demeanour

IJ’s appearance and demeanour, superficially at least, is of an overweight, ‘mother earth’, middle-class and capable woman. In her own home, I suggest she is stigmatised by this, firstly by her body size, then her casual, hippie/new-age clothing, her voice and presence as a confident, middle-class woman. This leads to the assumption that her disability is her fault and she does not deserve benefits. Any stereotypes linked to autism are absent because of the outsider’s focus on her external appearance. The stereotype of obese people being most pervasive, not taking into account the loop of pain leading to lack of mobility, leading to weight gain, leading back to pain. Puhl and Brownell and Schwartz et al argue weight bias is a

‘pervasive and powerful stigma’ based on implicit stereotypes of laziness, stupidity, and worthlessness, which is difficult to change (Puhl and Brownell, 2003:213; Schwartz et al., 2003:1033).

When IJ is at home, there is little indication she is autistic, although in autistic friendly spaces I have observed her flapping her hands when socially and sensorially overwhelmed. IJ says being autistic and middle class is a potent mixture. She says social, health, and housing workers do not understand when middleclass people cannot manage their lives. IJ says they work so hard to become middleclass; they have a discriminatory attitude to non-conforming middle-class people. She argues they view it as middleclass privilege versus the deserving poor.

IJ says people constantly perceive her as much more able than she is in a similar way to Blackburn, who says professionals perceive her as high functioning, because she is articulate, not appreciating her uneven profile of abilities (Blackburn, 2000; Booth and Happe, 2010). IJ says incorrect perceptions of her ability are the biggest barrier to getting others to respect her and her space, and in accessing services. IJ says she covers up her issues with memory and understanding so well sometimes she even confuses herself.

Society’s need for order

Sennett argues the middle classes fear difference, linking it to disorder, when faced with spatial practices they do not approve of (quoted in Woodcock and Smitheram, 2008:2). In this case both IJ’s embodied space as an obese woman, and the physical space of her home breach the mores of contextual and ideological spatial

expectations, returning us to Shilling's arguments in the framework for space in this thesis (Shilling, 2010:8,11). Burris and Rempel argue for many people their sense of self is dependent on maintaining an orderly world, to control their fear of mortality (Burris and Rempel, 2004:23,38). This need for self-protection is in turn linked to our primordial need to differentiate between 'in' and 'out' (Burris and Rempel, 2004:37f; Buss, 1995:9). Therefore, IJ's space is a threat to her community's spatial order and sense of identity on an existential level.

It gradually occurred to me that IJ focuses on parts of her maisonette when removing clutter, rather than seeing it as a whole, which could make its removal more efficient. However, over the two years I have known IJ this has not happened. There are two dynamics occurring here, firstly my socially conditioned wish to impose order on IJ's space and secondly concern that IJ despite her distress does not get to grips with its organisation.

A case of the need for 'pump priming' to improve efficiency

IJ, like Plimley's students, says the personal qualities of support workers are important in combating her inertia (Plimley, 2004:36). Using the example of pump priming, IJ argues you would not expect a machine to start or keep running without fuel or tell it to keep going 'because of the children'. She says the movements of others in her maisonette, gives her energy to do things, describing this as energy of activation, a term drawn from chemistry. IJ says that sometimes at the start of a task with her support worker, she has low-energy, which is increased by their support. However, when the task is finished, although her energy may drop, it does not drop as low as it was when she started. IJ described this as 'hitchhiking' other's energy.

However, IJ says if she is criticised or someone tries to control what she is doing her energy diminishes. In addition, IJ says she is reluctant to start a task 'without enough fuel', meaning she can run for a while, but then her energy runs out which is demotivating. This often means IJ often has support when she 'has no energy to do anything with it'. This meant recently she had let her support workers get on with clearing the maisonette, unsupervised despite breakages. However, she says this leads to her 'screaming, shouting and emptying her bowels every time anything important is broken or got rid of'. IJ says she feels emotion physically so will be sick, drop things or shake when she is distressed, her abdomen tightening, aggravating her IBS[31].

Not organising space – first thought - weak central coherence?

I wondered if IJ's apparent inability to organise her space was due to weak central coherence. However, her success as a painter and decorator and in remodelling the interior of her maisonette goes against this. I found another explanation in Happé and Frith's review of central coherence, where they cite studies that suggest depression/anxiety may lead to focusing on the detail at the expense of the whole; this may be the case with IJ who also has depression (Derryberry andTucker, 1994; Hesse & Spies, 1996 quoted in Happé and Frith, 2006:15).

Executive functioning

Another reason IJ suggested for being unable to organise her space was issues with

[31] Irritable bowel syndrome

executive function. One of the main tasks of executive function is planning and mental flexibility (Hill, 2004:27). Baggs describes her executive functioning as being equivalent to travelling on a wind thermal, sometimes she can do a lot, sometimes little, and sometimes things get done in a roundabout way (Baggs, 2006). Ettina says her issues with executive function concern the ability to be able to 'try', not because she chooses not to or because she has an emotional block; but due to lack of coordination between her frontal lobes and the rest of her brain, when she is attempting a task (Ettina, 2009).

Monotropism

IJ asked me to photograph the interior of the maisonette; my camera could only photograph a section of each room at a time. When I reviewed the photographs later I realised I had easily been able to frame them as pictorial compositions in their own right, whereas if I had been able to photograph the whole room at once the space would have looked chaotic. I considered this may have been how IJ designed and subsequently attempts to reorganise the maisonette, part of the room at a time, rather than focusing on the whole and I understood why IJ describes herself as monotropic. This means she can only focus on information from one sense or on one task at a time. First person accounts of Williams, Grandin and Lawson report similar experiences (Grandin, 1996; Lawson, 1998; Williams, 1996).

Therefore it is possible IJ focuses on organising a small area instead of coordinating her activities to reduce clutter in the entire maisonette, to those around her‘s frustration. Bonneh et al suggest autistics have a '… winner-takes-all mode of processing in which weak stimuli or representations are extinguished…' by those that

are more significant to them (Bonneh et al., 2008:648). Hughes et al suggest autistics do not perseverate in a global sense, rather they experience an autism-specific ‘stuck-in-set’ perseveration (Hughes et al 1994 quoted in Hill, 2004:27). Murray et al term this monotropism and as IJ explained her experience, I could see its correlation with this theory. Murray et al argue those working with monotropic autistics need to understand and allow time to accommodate their set-shifting issues (Murray et al., 2005:143).

Visit to a local community engagement meeting

On one occasion, we went to a community engagement meeting, as the time for the meeting approached, IJ and her friend began to bicker. IJ became tense, retreating to put a bra on under the dishevelled, grubby clothing she was wearing. The ‘mumsey’ look almost disappeared, she appeared unpredictable and defensive not helped by her wearing a black leather biker’s jacket. IJ started to behave like a naughty schoolgirl, trying to get a reaction. Later IJ said she is always jokey before she goes out, using it as amour to protect herself, because she finds the shopping centre we had to pass through, to get to the meeting threatening. IJ said this is because of the noise, lights, moving people, and goods on sale, which she is tempted to buy, although she cannot afford them, and the smell from cosmetic shops makes her feel sick. IJ says she finds sharing space with many people very tiring, whereas in a calm space she is more energised. IJ is also frightened she will not be able to walk home because of her arthritis.

During the meeting, IJ behaved in a similar way to when I had seen her previously. She sat at a table away from the main table where the other attendees were sitting.

Later IJ said she prefers to sit with her back to the wall so she can see the entrance to the room and where people are moving. The reason is that she is frightened by people coming 'up and out', always feeling something is creeping up on her, having a similar need to be able to escape as KM. In addition, IJ likes to have a space of at least a foot around her as she a does not like to be touched; so is on edge, fearing the pain this would cause, adding to her fear of sudden movement.

IJ said that wherever she is, she needs a table in front of her so she can doodle, which she uses as a calming strategy. She said she only survived so long in school because her teacher allowed her to doodle. IJ said the meeting room was comfortable, but she had not expected a formal meeting, or to be required to sit with others at a central table. Sitting still is very difficult, as IJ needs to move around. After the meeting, IJ stood and shook herself, which she says she always does after meetings to rid herself of stress.

Another reason for not sitting near other people is that IJ finds showering extremely uncomfortable, leading her to often not do so for long periods. IJ hates the feel of water on her body, exacerbated by not being able to get the water or the room to the right temperature. In addition, IJ is aware her breath smells because she has not cleaned her teeth since she lost her toothbrush abroad two years ago. IJ says she has a poor sense of time and gets ‘stuck’ on some objects and this is one example. Also, IJ says her bathroom always seems dirty because of the number of support workers and lodger's using it, meaning there are always traces of dirt and hair on the floor. However, when I used it I found it very clean, despite half of the space including the bath being taken up with trays of food.

IJ's relationship with Objects

IJ says she likes nice things, purchasing many items through eBay or using Freecycle32. IJ says she has lived in poverty for years, so purchases items when she has money, always fearing she will never have enough to buy them again. She said she had spent excessive amounts on bargain priced food because she was afraid it would run out, not considering repeat offers.

IJ says she is more orientated to objects, than attached to humans. She says her possessions and body size ground her, ‘keeping her in the world’, without them she feels she would float away or her ‘energy would spiral up and out of her head’. Similarly, she loves knowing her maisonette is built into a hill, describing the maisonette as a solid rock, with other maisonettes on top, giving her a sense of security. Sellin (1993) and Gerland (1996) also say objects represent stability and security to them, whereas they find people threatening (quoted in Baumers and Heylighen, 2010a:3; quoted in Baumers and Heylighen, 2010b:15). IJ said when she was at school she always took an object with her, a guitar, then a harmonica, a sheath knife on one occasion; these gave her a sense of identity and security amongst the bullying she experience. Frost and Gross argue objects give people a sense of security (Frost and Gross, 1993:367).

IJ says she has been described as a hoarder by statutory33 agencies but she rejects this label, saying her accumulation of objects is a response to external pressure.

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[32] Movement of people who exchange goods that otherwise would be discarded.

[33] Services, which the state in the United Kingdom has a legal duty to provide.

Russell et al also concluded from their study hoarding is associated with significant distress in autistic people (Russell et al., 2005:525). My impression from my previous, albeit limited contact with people who are overwhelmed by their possessions is the objects are often completely disorganised. In IJ's home, once I made sense of my surroundings, most of the objects, particularly those on shelves, were arranged in an aesthetically pleasing manner, when they had not been overwhelmed by large numbers of other objects. This suggests to me IJ has become overwhelmed by her space, more due to issues with executive function and hyperarousal than hoarding; IJ said she liked fitting her possessions into small spaces like a jigsaw, hence the presence of the cubed shelving. She says she likes things to look highly organised, arranged in colours and categories, having a liking for colour, complexity, random patterns, and overall symmetry. As our discussions progressed IJ said fixation on shapes rather than people is an indicator of autism in young children (Pierce et al., 2011). She said shapes were important to her; as a child, she had loved her shape sorter and her ladybird book of shapes. At the time of some of our discussions IJ was very distressed because her lodgers and the various support workers put things randomly on the shelves and in the cupboards. She says when things are moved she feels insecure her possessions representing 'constancy through time' and when they are moved or removed 'everything changes'.

Having her books out of order and not being able to read them all stresses IJ, the titles of the books shouting at her. IJ says she is hyperlexic, endlessly frustrated by redundant notices, for instance when she goes to the hospital, because she is compelled to read them all.

Neighbours and support services a case of being judged by your space

IJ’s home is located in a block of flats and maisonettes on a public housing estate where, she has considerable contact with her neighbours. This led to conflict from the outset, due to IJ not being aware of many unspoken spatial rules, such as not walking through public areas in muddy boots, making her unpopular. Tasks such as taking out her rubbish challenges not only IJ's mobility, as the route has steps, but socially challenges her; sometimes she is afraid to meet and have to talk 'even to nice people', as she sometimes is so depressed it challenges her social skills. This makes using the communal laundry daunting, each tenant has a specific time and day each week, which they share with another tenant. If there is conflict because your partner takes over or accuses you of taking over all the machines, or other neighbours decide to do their laundry on your day, disharmony results whether or not you have autism.

The biggest source of conflict arose when IJ was head of the tenants’ association. Eventually IJ stepped down, because despite raising considerable sums of money, including permission in principle to build a community centre, she had not realised she needed to keep detailed records of the association’s activities especially money transactions. She thought people would trust her and know the finances were in order. In hindsight, IJ says she realises she was naive but she had needed people to be brave enough to tell her where she was going wrong.

Jealousy

During this time, one of IJ's neighbours became jealous of her because she was more successful at running the tenant's association than he had been. This led him to harass her, spreading rumours verbally and through graffiti on the walls of the housing scheme. This spilled other tenants also becoming jealous of IJ as she has a larger maisonette than most and got permission to create a garden in front of her maisonette. The harasser's allegations also led to rumours she had misappropriated the association's money without the neighbours realising most of her possessions are second-hand.

This situation was not helped by the chaotic appearance of IJ's garden, visible from the blocks of flats and maisonettes surrounding it on three sides. This led to complaints about IJ's care of garden, her home, her pets, and her compost heap, alleged to be filled with rats. This meant her life became public and others became aware of IJ's vulnerability. For instance, she did not lock her door, because she often cannot get up to answer the door. This led to people entering her flat and, stealing items including her vacuum cleaner.

Others perception of IJ's space

I initially formed a negative perception of IJ's space and lifestyle, because I could not read the social and spatial cues of her home and did not understand the significance objects had to her and her issues in organising her space. This meant I was disorientated in her space; which impinged on my need for comfort and order. Instead, her space due to its smell and visual appearance intruded uncomfortably on my senses and challenged my social values. My expectation, until IJ and I discussed her use of her home and the issues it raises for her, was she would keep her home

clean and usable, especially as she had support workers and more especially as she had public money to pay for them!! Part of this attitude links to the stereotype of the 'deserving poor' and more especially to the 'compliant disabled person', making me complicit in 'business as usual disablism' (Kumari Campbell, 2008:152). Returning to the social stereotype of disabled people as objects of charity or heroes, and not socially challenging in anyway (Elshtain, 2010:241).

Section 2: MN a case of being assumed to be wilfully difficult

MN	Late forties, parent	Type II Fewer sensory issues, but more severe social issues, severe issues with executive function

In this section, I describe my visits to MN, my response to her, to her space, and our subsequent discussions in some detail. This is to continue demonstrating how autistic people's space and their demeanour create negative, self-perpetuating assumptions, and the impact of these on the individual's health, well-being, spatial functioning, and ability to access appropriate support services. MN is in her late forties and a parent, I describe her as having severe issues with executive functioning due to her issues with the organisation dialogue, and understanding documentation and the role and processes of various agencies meant to support her.

During the two years of this study, MN was confined to one room in her friend's flat, then later to her room in a hostel. She says her homelessness is due to the statutory services' failure to acknowledge she is autistic and provide trained support workers. Many people feel uncomfortable or threatened in presence of some autistics and I describe how I was both bemused and threatened by MN's demeanour and space. This was determined by my expectation of moderately calm demeanour and speech, organised in a relatively linear, reciprocal manner that led somewhere, rather than appearing initially to go around in circles.

To understand MN's spatial experience I returned to the hyphen, engaging in intense discussions, leading to MN like IJ and KM being very much a co-researcher. In the case of MN it was more her demeanour in her space, rather than her space that affected me. MN's living space was cramped, due to living in one room with most of her possessions. Each room provided enough room to walk to the bed and nothing else. MM said she was tidy until the birth of her children, but since then as she cannot multitask and having no support her surroundings became disordered. This became more so, when she moved to the hostel, despite daily support from an agency contracted to social services[34]. Although allocated an hour, MN said the support workers (two workers) came and went in fifteen minutes. The ashtrays and MN's beside table and other surfaces remained filthy; there were only superficial attempts to engage with her, the workers constantly changing. Even those I recognised from previous visits made no real attempt to work alongside MN. They did not arrive at the allocated time and limited their activity to emptying bins and washing crockery; not even washing the floor, although most of the dirt was brought in by them, entry to the room being directly from the outside.

Narrative of my visits

On my first visit to MN, she was in bed with an ethnic cotton blanket, tied sarong style under her arms. The only place for me to sit was on her bed. A laptop was on the bed on top of a piece of plywood, presumably to make it easier to use. There were shelves with haphazard arrangements of books, clothing, and other possessions placed behind the bed, with no room for a wardrobe or chest of

[34] UK government support agency

drawers. We talked and then MN walked outside and we sat chatting with her friends. This surprised me as during the two days when I first met MN she was always in a wheelchair. However, at her friend's flat, she was capable of walking outside when she wanted a cigarette or a joint, although she always returned to bed. I did not see MN prepare herself a meal or drink; her friend or one of their support workers funded by social services did this.

My second visit to MN came about because she was, according to her friend having an anxiety attack. The friend suggested I should go and make her some tea and toast. I went with some trepidation. When I got there, I faced a barrage of complaints about how MN was being treated. How no one understood her requirements, how anxious she felt, and how social services were letting her die. I found this emotive and to my mind exaggerated, I began to think she almost did not want a solution or to feel better. The biggest theme was no one understood her, so when I got a word in edgeways, I asked her what she wanted people to know and suggested I wrote it down. This slowed down what she was saying, as I had to write it down and gave her the sense she was being listened to. We made a list of urgent tasks the support workers needed to do each time they visited and what she wanted others to know about her and her family.

At first, I was nearly overwhelmed by MN's demeanour, as she talked quickly in what appeared to be an aggressive and overbearing manner, leading me to feel blamed for her situation. Although as a social worker I was good at being blamed for everything and regularly faced agitated and aggressive clients, she appeared far more unpredictable than they did. Appeared is the key word. MN says it is not her

space that threatens people, but assumption made about her, without people understanding the facts of her situation, and her experience as an autistic person.

This meant our interaction needed most of my resources to remain calm and centred. MN said she needed social services[35] to provide autism trained support workers and how hard her life was, which it undoubtedly was. This came out as a breathless tirade, without a pause for me to comment. I also felt an autism trained care worker may not provide the solution she was hoping for and could be problematic if their philosophy was informed by Applied Behaviour Analysis. MN's tirade, in this instance, appeared to focus entirely on her requirements with very little focus on her adult children's needs, one of whom also has a disability. Feeling disgruntled after my visit led to my expectation she would put her children's needs above her own, and expectation of many social workers. The next time I met MN she was in emergency hostel accommodation. Her room was on the ground floor, down a long corridor, with a heavy fire door halfway down. Half way between the front door and MN's room was the bathroom. The length of the corridor was about ten metres. MN said she could not walk to the bathroom due to difficulty with balance and the sensory stress of meeting other people. She said she also could not cross the meter and a half wide vestibule to get to the kitchen. MN also could not get to the front door to let her support workers in, due to her balance and there being no doorbell to tell her they were at the door, complicated by them always being late. The landlord would not allow a key safe for her room to be put on the outside of the building and

[35] Statutory government agency in the UK

the support agency refused to hold the keys. The support workers also could not ring MN to tell her she was there, as MN does not speak on the phone.

MN's room was about three metres wide and four metres long, a French window, allowing access to the room at one end. The cotton curtains were kept closed and the door slightly open, as MN's son was often there and smoked continually. This made the room cold, although they had a rickety halogen heater. MN was in a single bed propped up with pillows, her laptop in front of her. There were bookshelves against one wall and MN's son sat on an easy chair opposite the bed, surfing the Internet. There was also a chest of draws with a kettle, cups, different types of teas and other unrelated objects on it. There was a basic commode, with a rickety seat/lid between the French windows and the chair her son was sitting on. On the floor, was paper, crisp packets and empty beer cans, other objects and piles of boxes containing MN's clothing with her son's new bike in front of them. When I visited MN, her friend came with me. She said she felt guilty having only visited MN twice since she had been in the hostel. The friend said she found visiting too difficult as MN was so distressed and the room was so awful. That day the support workers had not visited for forty-eight hours, because there was nowhere to leave the key at that time for them to let themselves in. This meant MN's commode had not been emptied. Her friend did this, finding two more bowls of urine under the shelves and also emptied them. I could not smell the urine and it looked very pale leading me to wonder if there really was urine in the bowls.

The main smell in the room was underarm body odour. Incredulous, I concluded MN was probably going to the toilet etc. in the night. How could you stay in bed unwashed and with bowls of urine accumulating? I felt of course that MN must be

extremely distressed to be doing this. However, I felt it was more some kind of mental health issue than autism. This was not helped by MN's dramatic, confrontational, and muddled discourse. Her emotion appeared to be more anger, than concern and where there was concern, it was about herself. It is hard to describe but her presentation was not of trying to solve the issues, even in an unsystematic way. She constantly raged against social services, how she was not understood, and how she could not cope with speaking. She continually said she wanted to be nonverbal; however, in my opinion at the time, this was nonsensical, she did not want to speak - but never stopped talking. Also MN endlessly said everything would be ok if she had autism-trained workers, which I read as people who would do what she wanted, and wait on her hand and foot. The only way I could sense her distress was by her staying in bed to the extent she had urine in bowls, not by any sadness or vulnerability, in her voice or body language. Ragging, did not get sympathy, as it just felt as though she was trying to manipulate the whole situation.

Her vulnerability, in my opinion, was that she could/would not solve what was going on around her, staying stuck and homeless instead of filling in the necessary forms and jumping when social services said jump. Why stay in that room, why be so uncomfortable, surely, it was not just about being waited on and getting benefit.

On another visit, MN's friend had gone to considerable trouble to arrange a meeting with a solicitor to discuss the situation. Previously several solicitors had made and cancelled visits to MN possibly because word had got around about her demeanour and apparently intractable situation. MN wanted somebody to have her power of attorney, and to put pressure on social services to provide autism trained workers.

When we arrived at the hostel MN wanted to see me, there was no sign of the solicitor and the support workers were also due. The room and MN were very dishevelled. MN was still wrapped, sarong style in a cotton blanket. MN was clearly agitated. I felt we had to ‘ground’ the situation. I managed to get a word in edgeways eventually, and asked her whether she wanted to see the solicitor. She said she did, so I suggested she put a ‘t-shirt on. She pointed to an un-ironed baggy t-shirt she said she had worn when she was expecting her son. She then asked me to make the bed. She got up and wobbled unsteadily to sit on the closed commode. I began to get the cushions off the bed, when MN’s son sat on it looking at me out of the corner of his eye. I thought here we go. I said nothing and waited and MN told him to get off. MN’s son indicated he was rolling a cigarette as some sort of explanation, however, he did move. If I had said anything, I think there would have been a scene, the room certainly felt very tense. At this moment, one of the support workers arrived, let in by MN's friend who was waiting by the entrance to the hostel.

The room was filling up, MN, myself, MN’s son and the support worker. It was obvious the support worker had not been briefed in anyway about MN's requirements. The second worker did not appear. As soon as the support worker entered the room, MN’s face shrank behind her hair, her co-ordination and balance almost disappearing. She could not get her words out, having to point to what she wanted, as I tried to get her sheepskin the right way round on the bed. She was shaking from head to foot, her voice appearing to have to be dragged from deep within her when she tried to speak. The support worker emptied the commode and I pointed out the bowls under the shelves. In the middle of this the support worker said she had to go and move her car, as she only had parking for an hour. I thought she was probably using the car as an excuse and would not return, but she did. I then

became a mediator between the support worker and MN. It was clear MN became frozen with panic when she had to meet people she did not know.

Despite this in my shaken state, I still felt MN was self-centred, hard to work with, with some psychological issue meant she sabotaged every attempt at trying to get her life on track. I wondered if she was hooked on perpetuating her conflictual relationship with social services rather than face the tedium of poverty and loneliness.

However, this does not alter the fact that MN has been living in one room for two years, using a commode and a bowl to wash in. What seems to have been lost is historically she has almost never been able to get her needs met and function in a way that would be satisfactory to her and promote her ability to function. Perhaps lost because of assumptions made about her demeanour and a failure to find out what MN has to say. When those around her blame MN for being on benefit/not doing enough, they do not consider whether the payoff from being on benefits and support services is worth what some might hint, MN has engineered for the last two years. Especially when MN is so distressed by her encounters with the various support agencies.

When I reread this narrative, I felt my account was harsh, informed by many of society's and professional social workers attitudes towards those who do not conform. However, MN was keen this narrative was not weakened to demonstrate how the attitude of the professionals around her prevent her getting appropriate services and a fulfilling life.

What MN has to say

As before, IJ's account and our reflections are in grey boxes to distinguish them from the narrative.

MN says she feels social agencies judge her unfairly, for instance suggesting she has a personality disorder instead of autism, many of its traits being similar (Anckarsater et al., 2006). This is despite her having a diagnosis from an internationally recognised diagnostician. MN says this has led to thousands of pounds being wasted, forcing her into a situation where she is a burden on society. With the right support, MN says she is capable of working.

MN says social services and others 'invade her consciousness without realising the power of their thoughts'. She says she believes neuro typical conversation is nothing about 'what is really going on, but all about manipulation'. MN says social services say she is manipulative, but MN says she does not know how to do this, as she does not understand people. In addition, she asks where she would get the energy to 'manipulate all these people'.

A case of being a 'nonperson'

When MN discussed her emotions she said, 'I can't be unemotional about this when it is about me and my kid's life. The 'truth of me doesn't matter.' Something she said several times in our discussions. She said she is treated like a non-person to the extent that now she is beginning to feel like one. MN says she feels like she is being punished, by the support services and has to earn privileges, that she is seen as wilfully different. MN says she works so hard to be normal and is punished for being

different. MN asks, 'Am I supposed to be less than human because I have no carpets and curtains?' She says she thinks people want to prevent her asking for help. MN says she feels blamed, and made to feel guilty when asking others to do things for her, the attitude being that she should do things for herself. Through my support workers' glasses, this informed many of my attitudes in the narrative above. MN says how can anyone see that cannot is not the same as will not.

MN said she was aware people are scared of being in the same room as her. MN says she also feels tense in her room, as she rarely knows when the few people who visit are going to come, for long periods this is only her son, daughter or support workers. MN does not like people to knock on the door, as it is even more startling than having visitors open the door and walk in. MM says unexpected visits overwhelm her, as she has to process what the visitor is saying and then produce the required reply. MN says when she stressed this takes a lot of energy; not knowing who's coming through the door adds this, as she does not know what they will demand of her. The support workers change on a daily basis and MN never knows who will visit. MN finds it difficult when a new person starts, leading to her entirely cover herself under the refuge of her blanket. MN said sometimes she shuts out her support workers for three or four days, because 'having them in and out is like tidal energy' which totally distorts her balance.

MNs sense of balance

MN mentioned the effects of balance many times during our discussions. I gradually linked this to her sensory experience. MN says when she talks of extreme sensory issues she is not referring to a specific sense. Instead, she experiences her senses

as ‘altogether’, closely connected to her feelings, which are simultaneously linked to her centre and her concentration. She says her communication comes from her ‘feeling and energy of what she wants to say’. She says most people focus on their verbalisation of what they see, rather than what is beneath the words whereas her awareness is nonverbal. MN argues reference group membership shapes the reality of verbal people, distorting the disparity between their awareness and who they actually are. Thereby words become reality, disguising the disparity between what ‘reality’ is and ‘is’ which is the difference, MN says between the truth and opinion. MN argues this disparity between ‘truth and opinion, means ‘the reality defined by words is VERY different from the reality that just IS’. This awareness complicates speaking, especially if MN does not know what she wants to say verbally, as in this mode she cannot correct mistakes, as she does not understand the words she is speaking, although she may be talking fluently. She says this links to her sense of balance.

How social interaction affects MN’s balance

MN says ‘people get her spinning’ to the extent, she loses her orientation, exacerbated by her not having trained support workers to ‘assist her in her order’. An example of this she says is how typically developing people compartmentalise tasks, using a tick box approach, which MN says distracts her from her holistic awareness, losing it in the details of washing and cleaning, preventing her from ‘getting to the core’ of her requirements. MN says she cannot separate her sensing from her communication, therefore, when she speaks she has to say everything at once, before her balance is interrupted and she forgets what she needs to say.

How space affects MN's balance

Her living space also affects MN's sense of balance. She said she can just about use the kitchen, although she gets aurally and spatially overwhelmed by it because the kitchen is two rooms knocked into one, with part of the middle wall remaining, meaning MN always senses it as two rooms. She describes energy bombarding her as it bounces off the walls. The same thing happens in the corridor, complicated by the fact that anybody could be using it, which causes her anxiety. MN also says she cannot visualise the route between her room and kitchen, making it difficult to find her room again. MN's refusal to use the bathroom puzzled me, until I discovered the walls and ceiling are covered in a glossy chequer board of alternate navy and white tiles, which I also found overwhelming.

There are research articles across several disciplines discussing the link between anxiety, impaired sensory integration, balance, vestibular function and its effects on spatial cognition (Perna et al., 2001:279). Although most writers argue there is not a proven link between anxiety and vestibular function, this could be possible (Viaud-Delmon et al., 2011).

Not going out a case of balance

MN says she does not go out because she gets really lost, feeling like a whale, the sonar, or noises bouncing off the buildings. She has to keep her eyes open because she needs to be able to see the walls of buildings to keep up right, not automatically 'knowing where upright is'. She said sometimes she has to sit down in the middle of the pavement as everything is coming at once. MN describes waves of energy going through her. She says she picks up others' energy and feels invaded by their

emotions. MN says she needs to be still, living her life at a very slow pace, and feels constantly rushed by those around her. This means what is going on in the space of her body builds up until she feels she is going to explode. This is similar to Isthisreal's experience:

> I can't stop paying attention to the thing that's driving me nuts, and I can't escape it. Problem is, it's not just a particular noise. It's just sensory data, period: sounds, visuals going too fast, too many people, too much going on "energetically" wherever I am. If the situation is structured and quiet, it's better, but only for a while. If it's unstructured and noisy, forget it. I've tried to tough it out, but I've finally figured out that I just shouldn't be in those situations (Isthisreal, 2008).

Because of this MM will only go out with people she knows, who are trained, as she needs to know they can take over if necessary. MN says now, if she attempted to walk outside, this would be all she could do; she cannot walk around a shop and buy her food at the same time. So on the very few occasions, about four, she has been out of her room in the last 2 years, she has relied on a friend to take her in a wheelchair. This gives her the opportunity to choose what she wants to buy and talk to the person at the checkout, which she could not do if she was walking.

A case of a paralysing space

I was nearly overwhelmed by MN's space and demeanour. I realised the cramped room, with nowhere to store MN's belongings and lack of autism training, meant MN's space and demeanour overwhelms those meant to support her, hence their lack of engagement, leaving MN homeless, in unsanitary conditions.

A paralysing effect on those around her

The overwhelming nature of MN's space and demeanour, I suggest, leads those around her to feel a heady mixture of fear, frustration, and perplexity. In turn, according to MN's account, leading them to doubt her integrity, minimising the number of visits they pay, probably feeling she does not listen to them. The agencies possibly realise on some level MN is in distress, feel they have 'tried everything', and are left feeling deskilled, with the unconscious fear of their potential to be reduced to living in chaos and poverty.

A case of being paralysed in space

One of the main reasons for MN remaining homeless has been her refusal to sign documents because she does not understand what she is signing. MN says she cannot keep to a tenancy agreement, without support, having been evicted from her home seven times for non-payment of rent. Her refusal to sign documents has included those, which support her application to go on the housing waiting list. Housing agencies have tried to support MN but due to her difficulty in communicating with people she does not know, MN is perceived as uncooperative and denied a service.

MNs perception of her interaction with others

Below in figure 61 is MN's perception of herself in relation to the service providers around her.

Figure 61. MN's perception of herself and requirements in relation to the service providers around her

Paralysed interactional space

MN says a major reason for the perception of her as being difficult to engage is her difficulty in reading and matching the demeanour of others, which constantly catches her out. This is compounded by difficulty in following the rules of discourse, that it should be contextual and tailored to what the listener needs to know, or might be

interested in (Baron-Cohen and Swettenham, 1997:8). This prevents her getting her basic requirements for a permanent home and appropriate support met.

Because MN talks quickly, heatedly and always appears to be complaining, not allowing others to join the conversation, she appears not to listen, presenting as argumentative, aggressive and demanding. This led me to feel overwhelmed, de-skilled, and on the defensive, resulting in my sceptical stance illustrated in the narrative. My scepticism was compounded by MN's body language, tone of voice and the content of what she was saying not being with congruent, in my mind, with extreme distress that would gain my empathy and respect. An example of this is Shore's being told not to laugh by a co-worker, before going to ask his boss to leave early, because his parents had had a car accident (Shore, 2001:109). Similarly Sinclair said when he broke his ankle as a child, because he showed no emotion no, one would believe him (Sinclair, 2011).

In addition to MN's demeanour not appearing to match her distress (MN said her anger often comes out instead of distress) there was rarely a gap in her dialogue to ask for clarification or add my own comments. Intuitively it seemed counter-productive to intrude on MN's discourse as it might jolt from her stream of thought. MN confirmed this conjecture in the following quote from one of our emails:

> Another aspect is that i have holistic perception/experience and words are linear - when i am supported to speak from my holistic perspective, it is relatively 'easy' to do the 'translation' to verbal, and because i am speaking from my holistic perspective, it is also then much more likely that i will remember everything i want to say. however, it only takes a small

> interruption/disruption of some kind to throw me completely into chaos, because being in my holistic perspective AND being verbal is like walking a very fine tight-rope - it requires absolute focus and concentration and anything that interferes with that makes it impossible to 'stay in balance' and therefore i easily lose my 'balance' within that, and then what i want to say is gone - even in my non-verbal awareness [punctuation and spelling preserved from the original].

MN says she is often still learning the words for what she wants to say while she is talking, and even when she already knows the words, she is unable to match them to the context. This means she has difficulty in remembering what she wants to say as it takes a huge amount of effort to keep her 'non-verbal awareness at the level of words' especially as she does not have appropriate support from people who understand her issues. MN says when she knows the person who is supporting her and is provided with prompts, remembering and adding additional information becomes easier. This is borne out by my observation when I first met her of her happily chatting with her support worker and friends. This added to my confusion when she later talked of her extreme difficulty with being verbal. Baggs says she has had times in her life where she has had superficially good speech, an inability to speak or bad speech. Baggs says the act of communicating is not stressful, but speaking is. This is because as MN said, of the 'sheer momentum' needed to keep speaking. For Baggs this means when she does talk, she talks a lot as if she stopped, she could not easily start again (Baggs, 2008).

A case of wanting to be non-verbal

MN repeatedly says she wants to be non-verbal and this led to one of my biggest realisations from this study is that not everybody wants to use verbal communication. In addition, that someone who talks fluently must automatically find it easy. I found that some autistics due to issues with processing prefer to be non-verbal or use assistive technology (Baggs, 2000; Smith, 2005). Baggs writes regarding assistive technology, ‘I can enjoy things I could never fully enjoy before, because of the emphasis on speech’ (Baggs, 2000). When I have met people with similar issues to MN at conferences, there appears to be no difference in their speech, they speak fluently with no indication of their preference for non-verbal interaction. However, Smith argues speech, as we have seen in the case of EF and MN puts high demands on working memory, and you need to have a common language. In MN's case her presentation of both speech and body language do not conform to social expectations, leading to assumptions being made compounding her difficulty in engaging with others to get her requirements met. Smith also says speech alone, regardless of MN’s issues with balance, needs an instant response, and a high level of concentration (Smith, 2005). Additionally there is an assumption the ability to communicate verbally is consistent or improves rather than fluctuating between verbal and non-verbal depending on the physiological, interactional, attitudinal and sensory context of the space (Baggs, 2008). Gerland discussing these issues says turning words into speech is problematic for her and she seldom has time to say anything, whenever more than two people are involved in the conversation (Gerland, 1997:93).

MN says when she asks for support with her communication people automatically

assume they have to speak for her, without asking whether she wants to communicate verbally that day. This throws her into chaos as she might have prepared what she wants to say, and then cannot say it because the worker takes over.

Sense of time seeing the world from others point of view

Another aspect of KM's demeanour that bemused me was her apparent self-centredness. Other autistics write that they have difficulty seeing the world according to someone else's viewpoint. For instance finding it difficult to imagine a person having a life when they leave the autistic person's presence (WrongPlanet.net, 2008b). Also the idea that other people also have a mind full of thoughts is difficult (WrongPlanet.net, 2008b).This is referred to as not having a' theory of mind', not being able to understand the perspective of others and is often conflated with the view that autistic people do not have emotions or feel empathy (Lawson, 2001:198). Mulcahy suggests some autistics do not have situational empathy, that is while they experience emotions they may not show it in response to a particular situation (Mulcahy, 2012). In my experience there maybe gaps and misunderstandings, but autistics definitely have emotions and empathy; as with typically developing people it emerges differently in each autistic person. Also empathy can be obscured in autistics by multiple physiological, psychological, social and sensory processing that they simultaneously have manage to navigate interactional space and bodily spatial functioning (WrongPlanet.net, 2008a).

When I was with MN she appeared to be in a world of her own, policed by her own standards. Nazeer refers to this as 'autos' arguing many autistics can only operate

within their own frame of reference, feeling they can only rely on themselves (Nazeer, 2006:9). This is linked to impairments in executive function that would otherwise allow her to flexibly shift her attention, organise herself and focus on her goal which is to get appropriate services and accommodation for her and her children (Baron-Cohen and Swettenham, 1997:14). MN says she has no idea of how long things take and how various services work. Attwood terms this awareness ‘a sociosсheme‘ arguing it is ‘impaired’ in autism (Attwood, 2005:122). He describes this awareness, similar to autonoetic awareness, as of ‘me’ physically placed in the world as a separate, functioning body, and similarly of psychological ‘me’ as separate from others, located within a time continuum (Attwood, 2005:121). Attwood states autistics often have little awareness of time and are taken by surprise when it restricts their functioning (Attwood, 2007:122).

I infer from MN’s discussion of her conflict with service providers that her lack of awareness of their time and service constraints, adds to their resentment of her, which MN rightly says is not her responsibility. So whilst MN appreciates others have needs, she wants those around her remind her and realise she is often not able to do the joined up thinking to understand how the agencies attempt to work together to resolve her situation.

An overview of IJ and MN’s spatial experience and the assumptions it leads to

The common theme of this chapter is assumptions made based on IJ and MN’s appearance, demeanour, and organisation of space. As discussed in my analytical framework, Deleuze through his plane of immanence, argues we carry our past

experiences with us, which influence our current spatial experience (Deleuze and Boyman, 2001:29). My social work background suggested I suspend judgement, but my role as a support worker overtook this when I saw support workers doing tasks for, rather than alongside, feeding any doubts I had about IJ and MN's account of their experiences. This resulted in my becoming more judgemental than I have been comfortable reading. MN in particular did not want me to water down the account and on my part, again as with KM I felt it was important for the reader to go through the process of my experience to understand how easily situations can be miss-red with devastating consequences.

Controlling their environment

Control of their environment is a huge issue for both IJ and MN. Km in the previous chapter controls her space by having few possessions. Whereas IJ achieves a sense of control through having many objects, however, despite this, she feels out of control of her space and worries about the effect of this on others' perception of her. Neither IJ nor MN have a choice over who enters their home or who supports them. This highlights the fact that many autistics cannot choose where they live or who they allow in their home or who does their personal care, especially those who require intensive support.

The home as public space

Dyke et al discuss the home as site of caregiving. They suggest it is reconstructed physically, socially and symbolically through the blurring of 'private' and 'public' the home being (re)constructed as a space of 'caregiving' (Dyck et al., 2005:173). Certainly, both women presented a sense of feeling invaded and being out of control

of their homes, which affected their wellbeing, saying they felt morally judged by the appearance of their homes, rather than feeling safe, comfortable and in control. I got the sense the various agencies' expectations were based on the 'ideal family home' derived from nineteenth century expectations of nuclear family life, with the women setting certain standards of orderliness and cleanliness (Dyck et al., 2005:174).

Dirt

Cleanliness being linked with respectability and virtue and dirt with depravity and disorder (Cox, 2011:47). The presence of dirt, being linked to feelings of anxiety and disgust because it threatens spatial 'purity' (Watt, 2007:81). This is complicated by ever-increasing standards of housecleaning; there now being no daily or weekly routine as in the past. This means today cleaning is carried out when something looks dirty, making it an ongoing process, with no time limit, to the benefit of cleaning product manufacturers (Cox, 2011:54f,57). Along with this dirt is given objective status, whereas Wolkowitz argues it is socially constructed (Wolkowitz, 2007:15).

The home as a workspace

Therefore when support agencies perceive IJ and MN's homes as dirty and disordered and their demeanour as deviating from the status quo, whether consciously or unconsciously they may feel this reflects on their professionalism or otherwise (Dyck et al., 2005:176). This led to IJ and MN, reporting ever more acrimonious exchanges as the agencies attempted through, what Dyck et al term

'state practices[36]' to manage their space and demeanour. This meant their homes far from being the sanctuary they are for most of the rest of the population became a battleground of wills between them and the state (Dyck et al., 2005:182). This was to the extent of trying to force MN to walk and talk by not providing appropriate accommodation and services. This invades what Dyke et al term the 'vulnerable spaces of the body', which is what they suggest happens when care services enter the home (Dyck et al., 2005:174). In IJ's case, several of her support workers did not understand the significance of her possessions to her with the result that many objects were broken or put in the wrong place further undermining her ability to organise her space and wellbeing.

This means the privacy and autonomy typically developing people take for granted in their own homes is diminished for many autistics. Their homes and demeanour being exposed on a daily basis to the public scrutiny of support agencies, who in MN's case report to their managers daily (Dyck et al., 2005:181).

The reflection of autistic people's demeanour and space on the professionalism of support agencies returns us to the threat they present consciously or preconsciously to individuals membership of their reference group hence the often defensive stance taken by support agencies and workers.

[36] These include public housing, and public support agencies

Chapter 6: Conclusion

I chose the topic for this study in order to carry out an in-depth investigation into autistic people's spatial perception and functioning within the context of their daily lives to understand what makes this problematic from their perspective. This study cannot, and was not intended to be a comprehensive account of autistic people's experience; instead, it gives accounts of specific events located in certain times and contexts, recognising that experience is both dynamic and contingent.

My assessment was that this was lacking in the existing literature. This study is unusual because as far as possible, within the constraints of a doctoral study, I have attempted to work on an equal basis with the participants. This led to the development of mutual working relationships with the participants through member checking and discussion of the data, in some instances for the four years of this study. This dialogue ultimately led to my exploring and sharing with the participants how their spatial demeanour and in some cases their space affected my own spatial comfort.

Accordingly, the study moved from existing discussions concerning sensory issues, to moment-to-moment examinations of autistic people's functioning in the spaces of their daily lives. These spaces are predominantly social, full of interactional spaces, where we directly interact with others. The human and inanimate objects populating space present ever-moving socio-spatial cues, many unseen, unwritten, and difficult to articulate, influenced by ideological and contextual elements (Giddens, 1984; Sapir, 1927b). This study suggests that issues with preconscious processing mean many autistics experience space as a constant, immediate and incessant onslaught of demands that they cannot process fast enough (Gepner and Féron, 2009).

This means autistic people often miss or do not seamlessly adhere to socio-spatial cues, causing discomfort for those sharing the space. LeDoux (2003:267,303,ch 6-7) argues this is due to emotional arousal, innately conditioned by human survival needs, causing an instinctive wariness of those who are different to ensure survival (see also Burris and Rempel, 2004:37f; Buss, 1995:9). Another reason is it is not always apparent someone is autistic, as it often presents as a difference in demeanour rather than physical appearance. This is compounded as autistic demeanour, as shown in some of the cases in this study, sometimes appears as indifference to other's spatial requirements. This is exacerbated by an uneven profile of fluctuating abilities leading to often erroneous assumptions that autistics intentionally wish to cause spatial disharmony.

The effect on the autistic person of this spatial disharmony varies. EF and to a degree CD, either completely withdraw or hover on the margin of activities despite their qualifications. KM is constantly strategizing, trying to work out what the rules are and how she can either navigate them or circumnavigate them and what she can do to restore the status quo if they are unsuccessful. OP cannot think if there are certain noises, which means he may appear aggressive, simultaneously not being able to explain what is wrong until the noise passes. Others such as IJ and MN find others' assumptions regarding the appearance of their homes, lifestyle, and demeanour affects their ability to access appropriate services.

Space as conceptualised in this study

Given the shifting nature of social and interactional space and its socio-spatial cues, abstract constructions of space or those focusing on its visual and aesthetic properties are not broad enough to account for autistics' spatial experience.

Consideration of the sensory and physical demands of space are still important, but autistics' daily spatial functioning in real-time also need to be examined including the effects of preconscious processing.

This understanding has led to the development of my typology of space, which focuses on elements, whether physiological or social, that affect spatial comfort in the immediate, interactional space of moment-to-moment encounters with others. This understanding is therefore set apart from Bronfenbrenner's ecological systems theory and Smith's amalgam of physical and social space in school classrooms, which focuses on the dynamics around the learner rather than the learner's immediate interaction with those around them (Bronfenbrenner, 1976; Smith, 2007).

My typology suggests that the demands of social and interactional space are determined by ideological and contextual elements that shape its socio-spatial cues. Experience in interactional space became one of the major focuses of this study.

Autistic peoples' perception and functioning in space: what makes this problematic?

Physical and sensory aspects of space compound issues with reading socio-spatial cues. Most design discussion to date discusses sensory issues in isolation without presenting a detailed account of their underlying physiological processes and how these also affect social aspects of spatial functioning. This study combines both.

For KM, disunified vision means she cannot filter and unify what she sees fast enough, adding huge demands to her processing of all aspects of space leading to exhaustion and in extreme cases shutdown. In the case of MN she senses energy 'bouncing off the walls', and describes how she needs to see buildings to know which way is up. Managing the sensory demands of physical space disorientates her

within interactional space interfering with her ‘holistic awareness’ as she cannot separate her sensory experience from her thought and communication processing. Therefore articulating her requirements is a struggle, as she attempts to say everything at once. Those sharing space with MN become overwhelmed by what appears an aggressive and demanding 'attitude', appearing to freeze some agencies’ attempts to support her. This also exacerbates other workers’ frustration with MN and her situation because it threatens their social competence and reference group membership, i.e. that of compassionate and effective support workers (Shibutani, 1955).

Effect of autism on physiological processing of socio-spatial stimuli

Lack of modulation of demeanour is an important example of how autistics can unintentionally disrupt others’ spatial comfort. I applied Ben Shalom’s integratory theory of autism to this study to account for this and other issues in meeting the socio-spatial demands of space. She suggests three levels of processing in the four domains of motor, emotion, memory, and sensation/perception. These are unconscious processing, level 1, preconscious processing and integration, level 2 and logical, conscious processing, level 3, which are important in the context of this study to understand autistic peoples’ socio-spatial functioning. Her theory suggests lack of modulation is due to issues with preconscious integration of socio-spatial stimuli at level 2 (Ben Shalom, 2009). As an example, an experienced cyclist will be relatively relaxed, even daydreaming, on approaching a set of traffic lights. A less experienced cyclist will consciously have to think where their feet and hands are and will be apprehensive as to whether they will safely navigate the junction. This latter is a conscious process, whereas the experienced cyclist through constant repetition of

the coordination required to move off at a junction will largely rely on habit at level 1, combined with preconscious processing at level 2. The less experienced cyclist, just becoming accustomed to cycling, will consciously juggle their coordination at level 3 to create impetus to move from the junction, not being able yet to fully predict whether this will be successful.

Many autistics never achieve this coordination according to Ben Shalom's model, their processing of socio-spatial cues staying at level 3, throughout their lives. This means that instead of seamlessly and preconsciously integrating socio-spatial cues they retain a reliance on rules created using logic. These are not nuanced enough to meet the contingencies of the fluid nature of socio-spatial interaction. This causes ongoing anxiety, many autistics never being able to predict whether their rules will work and what the consequences of failure might be, meaning they are often at a disadvantage during socio-spatial interaction.

From the data, I will now provide an overview of issues with preconscious processing in all four of Ben Shalom's domains.

Motor

In this study, the two most significant effects of differences in preconscious processing in this domain relate to motor action and planning, and spatial perception.

Motor action/bumping into people

As I conducted my case studies I was struck by their reports of being jostled and bullied on public transport. In KM's case, she articulated an inability to preconsciously integrate the motor actions of others to predict which way they were going to move. In turn, she cannot integrate her motor actions to produce the body

language to indicate where she is going. Another aspect of this is her absence of body awareness, complicated by disunified vision, seeing ‘everything’ in its raw unintegrated state. Ben Shalom describes this as moving ‘exogenously’, responding to socio-spatial stimuli instead of the autistic person initiating their own response (Ben Shalom, 2011c).

Motor processing – the effect of disunified vision on object recognition

Across the case studies it was evident how far motor processing and planning dominates many autistics’ lives as it takes so much conscious effort to exist. For KM, a significant part of her processing load is due to what she describes as disunified vision, which means she sees objects at Ben Shalom’s level 1 as ‘perceptually defined parts of objects’ (Ben Shalom and Clemerson, 2011). This means when she sees an object for the first time she can name it using logic at level 3, but cannot preconsciously integrate its parts at level 2. Instead, she has to consciously integrate it at level 3 before she can use it. If KM uses an object or a space repeatedly she relies on habit at level I and procedural memory. However, in an unfamiliar space or with unfamiliar objects she has to visually unify them first. Therefore, when KM can control her space she has as few objects as possible. In those she cannot, she is constantly using compensatory strategies to conserve her processing power to prevent shutdown. As we can see from the case study, preference for machines and public transport with limited or no social interaction is because they place fewer demands on her processing.

Motor processing - speech

EF has difficulty in speaking and making himself understood. Speaking requires preconscious motor integration to coordinate movements of the mouth, teeth, and

lips to control the breath to shape words to produce sound. This also affects prosody as we saw in the case of OP, whose tone, pace, and punctuation of speech, constantly drew the attention of those around him.

Emotion

The case studies show that the spatial comfort of both autistic and typically developing people is highly dependent on their emotional state and ability to preconsciously read the emotions of those around them. The consequence of such preconscious ‘reading’ is to create an emotional connection, however fleeting, with those around them. The presence, absence or quality of this connection is an important determinant of spatial comfort. The case studies confirm that for many autistics, in addition to issues with unifying vision, integrating their own and others’ motor actions, their emotions remain in a raw state of unconscious processing at level 1. This makes it difficult to modulate or shift from one emotion to another and preconsciously integrate the complex emotions of others to understand them. This is compounded by many autistics’ emotions, for instance those of KM and MN, being dominated by hyperarousal, anxiety, and/or being constantly in a state of fight or flight because of sensory and social-spatial demands.

This study showed that issues with in integrating and presenting emotion may be subtle – CD, EF, and OP always seeming slightly out of step, exemplified in the instances when the woman was trying to direct CD, and the solicitor was pointing out the toilet paper on EF’s foot. Emotion works together with motor action, sensation, and perception to create ongoing subtle shifts in demeanour. These cue to others who you are, your likely behaviour, your interest in what they are saying, and whether you are ‘like them’, and therefore likely to pose little threat. This requires

intricate preconscious processing at level 2, whereas the logical processing at level 3 is often not nuanced enough to deal with contingencies of specific spatial encounters.

The effect of autistics' emotional state on the spatial comfort of others

In this study, KM's and MN's cases illustrate the influence of issues with preconscious processing of emotion on the development of erroneous assumptions about autistics. KM could not integrate the complex emotions I experienced on the journey, which overwhelmed her senses threatening to cause her to shutdown. To avoid this KM purposely alienated me. In MN's case, the extreme nature of her emotions and demeanour threatened me. In both situations, I was left feeling vulnerable and de-skilled causing a defensive reaction, leading to erroneous assumptions. This was because my social and professional competence and reference group membership was threatened, I felt a loss of face, despite trying so hard to understand (Goffman, 1972:9).

The social problems that emerge tend to compound the original problem. We expect to be rewarded when we make an effort to be understanding, so there may follow a punitive reaction when the person does not appear grateful. This leads to further distress for autistics. Another important point I discovered through my ongoing contact with KM is that no matter how long I have known her I still often have an intense emotional reaction to her extreme emotion, particularly of anger because I attach a host of other emotions to it that she did not intend me to feel. The result can be as KM pointed out a logical disagreement becoming an emotional one.

Memory

The two most important aspects of memory affecting spatial use highlighted in this study are those of episodic and short-term memory. Episodic memory is the memory of self in past events and short-term memory is the temporary storage of information in this instance that required to participate in conversation.

Episodic memory

Episodic memory requires preconscious integration of its associative components that bind events into cohesive episodes and strategic components that allow past events to inform future ones (Shing et al., 2008:495). This is crucial to wayfinding and informing future socio-spatial demeanour in similar situations. As episodic memory requires preconscious processing the case studies show that autistics compensate by using rules created using logic at level 3, using procedural and semantic memory to remember past events. Again these rules are not nuanced enough to meet the contingencies of everyday life. KM, for instance, could not visualise places she visited regularly, so on the journey it was futile to blame her for her discomfort by expecting her ‘to have known’. KM compensates for lack of episodic memory by using semantic memory to remember conversations and in remembering text on road and building signs.

Effect of issues with preconscious integration of episodic memory on spatial organisation

KM caused her family consternation because she would not buy furniture or have renovations done to her apartment. This was because she could not visualise how her apartment would look when furnished, compounded by the fear that furnishing the apartment would cause sensory distress, as the visual and motor processing

demands of the new items may have overwhelmed her. This demonstrates the role of perceived inflexibility as a legitimate strategy to support spatial functioning.

Effect of short-term memory on conversation

Understanding the effect of issues with short-term memory is crucial to understanding some autistics' reluctance to join in or being out of step during conversation. In EF's case, this could have been assumed to be due to difficulty in speaking. However, EF says it is compounded by his poor short-term memory. This means he cannot remember what each person has said, and structure his response accordingly, to insert his contribution without interrupting flow of conversation or the argument being made (MRC Cognition and Brain Sciences Unit, 2008; Poirier and Martin, 2008:245). Also some studies indicate autistics do not use inner speech to verbally rehearse what they wish to say, something typically developing people do before speaking (Poirier and Martin, 2008:240). Short-term memory is also an executive function compounding issues with sequencing dialogue (Kalbfleisch and Loughan, 2011:123). These are conscious processes for many autistics that not only involve remembering what to say, but also processing, presenting and reading the in-process socio-spatial cues. The person also has to simultaneously plan the associated motor actions not only to speak but to present the expected social demeanour, with the result that many find speaking for any length of time very tiring. Again, they run the risk of being out of step and like EF they avoid socio-spatial interaction not because they do not enjoy it, but because it is so difficult to successfully navigate the socio-spatial cues of interactional space.

Sensation/perception

Issues with sensation/perception compound issues with preconscious processing in the four domains. The main concerns discussed by the participants in this study were disunified vision, noise, light, and balance.

Disunified vision

For KM, disunified vision rather than ‘lacking theory of mind’ makes it ‘difficult for her to recognise faces and the emotional states of others. Disunified vision, combined with not being able to move her eyes also makes it difficult to scan environments and participate in joint attention, resulting in KM not being able to find servers in restaurants or find a taxi for instance. Her processing of her environment is slowed by her disunified vision both in the reading of and presentation of socio-spatial and physical cues for motor tasks and social interaction. Additionally, as she cannot preconsciously filter visual information, eyes with emotional content or a questioning gaze could be painful to look at.

Noise

The participants in this study made a distinction between two types of noise. For KM this is divided into noise without content, for instance the steady beat of a power drill, which she can sleep through, and noise with content such as speech and music which KM finds painful even though she is a musician. Conversely, OP cannot tolerate noise with a beat, such as that at road crossings, the base from stereo systems and worst of all high heels. OP always chooses places where there is little echo; simple design features such roof beams, wall and floor coverings reducing its effect. Debra had the most difficulty with sudden noise, which could also lead to shutdown for KM.

Light

Light, in particular fluorescent lighting was an issue for many of the participants, KM at the most extreme end relying only on the light from her room heater. The effect of fluorescent lighting was reduced somewhat if the fluorescent tubes were all of the same age, requiring only one flicker rate and one colour to process; different age tubes having different colours and flicker rates, imperceptible to most typically developing people.

Balance

For MN, as discussed earlier, balance is a major issue, affecting every aspect of her sensory processing and executive functioning, including memorising and sequencing tasks and what she wishes to say.

Air pressure

KM is sensitive to air pressure, which means she does not use her air conditioning in summer or winter, because it creates different intensities of airflow in her apartment. Although KM wears long-sleeved tops and long trousers the different parts of her body register these changes in airflow, constantly requiring extra bodily processing. Blakemore et al found an implied specific hypersensitivity in the Pacinian corpuscles receptor pathway that may account for this (Blackemore et al quoted in Elysa J. Marco et al., 2011:49).

Executive function, assumptions, demeanour, and the home

The significance of objects

Absence of objects in KM's apartment gives visitors few spatial cues as to the demeanour expected by visitors, in the absence of these cues others take over her

space, for instance during the vet's visit. In my case, lack of physical, spatial cues left me in limbo not knowing what was expected of me. This shows how significant objects are in determining our spatial comfort by indicating socio-spatial expectations, for instance where to sit.

However, in the case of IJ her objects had the opposite effect. There were so many, others were overwhelmed by them, often missing their importance to IJ as a strategy for 'keeping her in the world'. The large number of objects undermined IJ's support workers' ability to appreciate where IJ's space was organised to return her possessions to the correct place and prevent them being damaged.

Negative perceptions of IJ's organisation of her home together Issues with executive function led to erroneous assumptions being made about her and her lifestyle. Similar assumptions were made about MN. Both appear middle-class and intelligent. Because they are women there is an additional expectation that their home will be clean and tidy. For IJ negative assumptions about the organisation of her home were exacerbated by her being overweight. These assumptions were polarised because both IJ and MN received support from external agencies. This meant their homes shifted from being personal sanctuaries to semi-public workspaces of others, a situation faced by many autistics. As semi-public workspaces, the condition of IJ's and MN's homes was seen to reflect the competence of the support workers and organisations. This brought their lifestyle and demeanour under intense scrutiny by support workers they had not chosen, causing ongoing conflict because IJ and MN did not meet the workers' expectations.

Final thoughts –implications and future work

This study and its conclusion only provides a brief overview of the complex, simultaneous issues that make autistic people's spatial perception and functioning problematic. It intentionally does not provide a derivative tick list of spatial requirements for spatial design for autistics. Instead, it provides a snapshot of the participants at a certain point in their life continuum, recognising that this and space itself is continually in a process of becoming that is never finished.

Therefore, the study suggests a new way of approaching the design process, which starts from working alongside all end-users of all built environment projects on their terms and focuses on creating spatial comfort and sociability before dimensional and aesthetic considerations. This involves educating the public to have a critical awareness of their own and autistics' spatial design requirements. Designers need to move from assuming the role of experts to becoming facilitators of built environment or product design. Design according to this philosophy needs to be seen as an ongoing process of dialogue between the public and designers to address the emerging spatial requirements of all. This means design for those with specific requirements is not merely a matter of tacking on a ramp at the back of the building or training people to be 'autism aware'. Nor it is a question of 'understanding' 'explaining', justifying, or encouraging 'toleration', but acceptance and the recognition of the right for everyone to be able to enter buildings through the same door, participate in employment, travel, leisure, and other activities not just as a right but as an automatic expectation. Inclusion, like design, needs to be seen as a continual development to accommodate the constantly evolving nature of society and space.

For those who plan services for the autistic community

Those such as Grandin suggest that ‘multiculturalism is most effective when different cultures can make changes and partially adapt to each other’s ways’, and that autistic people need to be stretched (quote from viva examination). Taken uncritically, these are commendable goals. However, as Rowan Williams argues it is not different cultures that less dominant cultural groups have to adapt to, but a Western monoculture based on accumulation (Williams, 2007b:1). This culture may support difference, even to the extent of legislation; however, this is still based on toleration rather than mutual respect. Both Rowan Williams and Brown argue it places the ‘other’ or ‘object of toleration’ as in need of protection, which prevents authentic participation and reciprocal influence, requiring tolerance and therefore as a lower form of life” (Brown 2006, quoted in Campbell, 2010; Williams, 2007b:3).

This imbalance means there is a division between those living in the community absorbed like many people in bringing up children, and/or finding and holding down jobs; or meeting the requirements of academic courses. Some do all three and have to manage all the relationships and the many misunderstandings this may involve. For those such as MN, all her energy is taken up with trying to get her support needs met, somewhere to live for her and her children, and organising meals and laundry in one room, in a hostel that is not accessible, with a shared kitchen that sensorially overwhelms her.

The other group are those who live in institutions, their support largely centres around keeping them safe and healthy; them and their homes clean, and monitoring and controlling their behaviour. Again commendable aims, being largely the goal of support which MN intermittently receives.

The effectiveness or not of these activities are relatively easy to quantify, whereas the results of mentoring may be less easy to measure, hence neglect in this area. As I discussed earlier, I believe that mentoring should not be at the expense of allowing autistics to get into debt or the deterioration of their property and health. However, I agree with Grandin, that all autistics, in fact, everyone should have access to activities, which give them a sense of fulfilment in alignment with their aspirations.

However, the provision of mentors is problematic; Grandin often refers to the importance of her relationship with her mother and her strict upbringing in enhancing her functioning. The key reason for this success I suggest is that Grandin appears to have a very strong attachment[37] to her mother and trusts her implicitly. However, unlike Grandin, many autistics especially those in institutions may have no living parents or have never been closely attached to them. This often means they have no role model, no one sometimes, who has even a basic understanding of their requirements, and often no one they can trust. This is compounded by institutionalised autistics not being able to choose who works with them, and the workers not being matched according to affinity of interests and/or background, compounded by a very high turnover of support workers. Cleaning and controlling on its own relatively rarely produces healthy, stimulating relationships and rewarding work. Additionally, institutional living arrangements for autistics, even when apparently living in the community may involve three to four changes in staff per day; one person may support the person to get up, another for lunch, another for the evening meal, and another for going to bed. Some visits being restricted to fifteen or

[37] Here. I am applying Bowlby's theory of attachment (Bowlby 1977).

twenty minutes or less, focused on care and safety; rather than creating a quality relationship that would create an environment for meaningful activities, with a sense of achievement for both, enhancing the lives of autistic people and support staff possibly enhancing retention.

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